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The Role of Occupational Therapy in the Prevention and Management of Chronic Conditions at a Free Primary Care Clinic

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The Role of Occupational Therapy in the Prevention and Management of Chronic Conditions at a Free Primary Care Clinic

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CERTIFICATE OF APPROVAL

This is to certify that the thesis of

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Abstract

The prevalence of chronic conditions is a growing public health concern in the U.S. The physical, social, and emotional impacts of chronic conditions are exacerbated by social and physical determinants of health, resulting in occupational injustice. This study took place at a free primary care clinic, the Ithaca Free Clinic (IFC), and set out to determine the need for occupational therapy services for the prevention and management of chronic conditions, supports and barriers to clients participating in occupational therapy services, and supports and barriers to providers referring to occupational therapy services. Results of this study indicate that clients with chronic conditions could benefit from occupational therapy to address the everyday impacts of their condition(s). Clients without chronic conditions could also benefit from occupational therapy to prevent the development of chronic conditions. Both personal health beliefs and social and physical environmental barriers impeded clients' participation in occupational therapy services at the IFC. Referrals to occupational therapy services can be better facilitated by attending to internal barriers specifically at the IFC and educating other health professionals on the scope of occupational therapy. Outcomes of this study add to literature supporting occupational therapy intervention for this population and aid in advocating for this emerging practice area.

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Dedication

For Dad, Mom, Rachel, and Leah. You are my rock.

Table of Contents

Chapter One: Introduction

Preamble

Compared to other developed nations, the U.S. has one of the highest rates of hospitalizations and avoidable deaths (Tikkanen & Abrams, 2020). Chronic conditions are often preventable, and yet six in ten U.S. adults have a chronic disease, and four in ten have two or more (Centers for Disease Control and Prevention [CDC], 2020b). Chronic conditions are characterized as "conditions that require ongoing medical attention or limit activities of daily living or both" and last a year or longer (CDC, 2020b, para. 1). The already concerning pervasiveness of chronic conditions is only continuing to grow. According to Bodenheimer, Chen, and Bennett (2009), the prevalence of diabetes is projected to increase 100% and spending related to diabetes care is projected to rise 53% by 2034. Therefore, attention to the prevention and management of chronic conditions is needed to improve healthcare services and health outcomes (Raghupathi & Raghupathi, 2018).

The complexity of chronic conditions has brought this urgent public health issue to the forefront of healthcare discussions. Chronic conditions are defined as conditions that last a year or longer and have long-term and ongoing implications (CDC, 2020b). It is important to note that mental illnesses are also considered chronic conditions, and there is a relationship between physical and mental illness (U.S. Department of Health and Human Services, 2010; Cleveland Clinic, 2020). Mental illness can arise as a result of chronic physical conditions and mental illnesses, such as depression, can increase the risk of developing physical conditions (National Institute of Mental Health [NIMH], n.d.). The magnitude of both physical and mental chronic conditions in the U.S. is a significant

public health concern and calls for a closer examination of how they are perpetuated within communities.

Lifestyle choices, such as lack of a healthy diet, physical activity, excessive alcohol use, and tobacco use and secondhand smoke are often discussed as causes of chronic conditions (CDC, 2020b). However, it is important to also consider the role environmental factors play in the development and aggravation of chronic conditions. Access to healthcare, food resources, safe housing, and other social determinants of health (SDOH) can either contribute to illness or work to maintain health and prevent disease, especially chronic conditions (Cockerham, Hamby & Oates, 2017). SDOH are defined as "the conditions in the environments in which people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks" (Healthy People, 2020a, para. 5). Certain communities and populations are disproportionately impacted by SDOH, which results in health disparities.

Individuals with chronic conditions are an example of a population disproportionately impacted by SDOH. For instance, individuals with lower socioeconomic status experience decreased access to valuable health resources, such as grocery stores with healthy food options (Pampel, Krueger & Denney, 2010). Perhaps the most impactful SDOH, however, is limited access to healthcare due to lack of insurance coverage. Based on a 2019 survey, an estimated 32.8 million adults under the age of 65 were uninsured at this time (CDC, 2020c). Many people remain uninsured due to lack of employment tied to insurance, limited awareness of financial assistance under government policies, such as the Affordable Care Act, and/or status as undocumented immigrants who are not eligible for Medicare or Medicaid coverage (The Henry J. Kaiser

Family Foundation, 2017). Furthermore, the rates of Hispanics and Blacks who are uninsured are up to double those of Whites (The Henry J. Kaiser Family Foundation, 2017). Because individuals without health insurance are more likely to seek out medical care, they are less likely to be diagnosed with a chronic condition or an existing chronic condition can go unmanaged (The Henry J. Kaiser Family Foundation, 2017).

As the symptoms of chronic conditions become more difficult to manage, participation in daily valued activities can become challenging (American Occupational Therapy Association [AOTA], 2015). According to AOTA (2020a), the inability to participate in meaningful occupations can negatively impact health and wellbeing. Therefore, this population experiences occupational injustice, or inequities in accessing or participating in healthful occupations (Hocking, 2017). Furthermore, since minority racial groups are more likely to be uninsured, these individuals experience additional occupational injustice in terms of access to health care. Occupational therapy (OT) intervention is needed to both prevent and manage chronic conditions in adult populations. Concepts of occupational justice must be applied to mitigate the impact of SDOH, especially for at-risk socially disadvantaged populations, whether they are disadvantaged due to socio-economic conditions, access to healthcare and transportation, exposure to crime, and/or discrimination (Healthy People, 2020a).

In their practice, OT practitioners consider the dynamic interactions between the client, the occupations they engage in, and their overall context (AOTA, 2020a). Furthermore, OT practitioners are holistic in their practice, as they view clients as occupational beings whose occupational participation may be impacted by chronic condition(s), client factors, context and the environment (Leland, Fogelberg, Halle &

Mroz, 2017). As environmental factors, such as SDOH, contribute to the development and worsening of chronic conditions, the distinct skillset of OT practitioners is particularly relevant to this population. For example, OT practitioners can facilitate evaluation and adaptation of lifestyle choices such as social engagement, physical wellness, and mental health, therefore helping to prevent chronic illness (Bruzzese, 2017). In turn, OT practitioners can decrease financial burdens associated with care and simultaneously improve individual quality of life (Bruzzese, 2017). OT practitioners can also address prevention of illness, promoting positive mental health, mitigating health disparities, managing mental illness using coping strategies, specifically primary and secondary prevention of chronic conditions, and more (AOTA, 2020b).

OT practitioners work with individuals with chronic conditions and those who are at risk for developing chronic conditions through involvement in community-based settings, such as primary care clinics. Halle, Mroz, Fogelberg, and Leland (2018) asserted that health management, wellness, and prevention, all historic aspects of the OT profession, align with the primary health care model. Primary care was defined as "a whole-of-society approach to health and well-being centered on the needs and preferences of individuals, families, and communities" (World Health Organization [WHO], 2020c, para. 1). Specifically, OT practitioners can assist in decreasing hospital admissions or readmissions, increasing medication adherence, providing early intervention and care coordination, managing chronic conditions, and preventing long-term care, in primary care settings (Halle et al., 2018). While the presence of OT practitioners in primary care is slowly growing, the profession faces several barriers to

involvement in this setting, including reimbursement, misunderstanding of the scope of OT, and appropriate education for OT students (Halle et al., 2018).

Scope of the problem.

OT practitioners have traditionally worked with clients on an individual basis, however, they must also view health issues at the population level by considering the needs and conditions of the greater community (Braveman, 2016). Intervention with individuals who have chronic conditions is well within scope of OT, however, literature regarding OT intervention with this population in community-based settings is scarce. Therefore, further research is needed to explore the need for the OT profession's role in the prevention and management of chronic conditions in community-based settings, such as primary care clinics.

Statement of Purpose

The purpose of this study was to determine the need for OT services at a community-based free clinic, the Ithaca Free Clinic (IFC), for the prevention and management of chronic conditions. Additionally, this study aimed to identify the provider and client views of OT services for chronic conditions at the IFC. Finally, this study investigated supports and barriers clients experience in terms of participating in OT services and supports and barriers providers experience to making referrals to OT services at the IFC.

Research Questions

1. What is the need for OT services for the prevention and management of chronic conditions at the Ithaca Free Clinic?

2. What are the supports and barriers for clients at the Ithaca Free Clinic participating in OT services?
3. What are the supports and barriers for providers at the Ithaca Free Clinic in referring clients to OT services?

Limitations

This study gathered participant data using an anonymous survey and therefore was unable to provide any significant qualitative data. An originally planned supplemental focus group with clients and providers could have provided richer data, however, this was not feasible due to time constraints. Furthermore, the study was not limited to clients who currently have a chronic condition, as OT services may be beneficial to those at risk for developing a chronic condition as well. This inclusion criteria could have been confusing for clients responding to the survey, as many of the questions address chronic conditions. Finally, a small sample of both clients and providers was used in this study and so limited data was collected. The scope of this study was limited to clients and providers of the IFC, and therefore cannot be generalized to the greater population.

Delimitations

Data for the current study reflected clients and providers at the IFC only. As the topic of this study is broad in nature, investigating a single population within the local community served to narrow the scope of the study. The study focused solely on this location and results may inform current practices at the IFC, especially since only current clients and providers were asked to participate in this study. Specifically, the results of

this study are beneficial to IFC administrators and providers, as they suggest reasons for decreased participation in OT services and can therefore serve to increase participation.

Assumptions

The primary investigator (PI) assumed varied reading levels and vocabulary when creating survey materials and that participants would understand the questions. The PI also assumed that all participants responded honestly to survey prompts and matched the inclusion criteria.

Definition of Terms

Chronic condition: "Condition that lasts one year or more and requires ongoing medical attention or limits activities of daily living or both" (CDC, 2020b, para. 1).

Health disparities: Disease, injury, violence, or overall poor health that is preventable and disproportionately impacts socially disadvantaged populations (CDC, 2018).

Multimorbidity: "The co-occurrence of two or more chronic conditions" (Navickas, Petric, Feigl & Seychell, 2016, p. 4).

Occupational justice: Facilitating equal opportunities to engage in occupations that are just, health-promoting, and meaningful (Hocking, 2017).

Occupational injustice: When social conditions impacting groups of people differently give rise to inequities in accessing or participating in healthful occupations; where some people benefit and others experience occupations that are harmful to health and well-being (Hocking, 2017).

Occupational deprivation: When external aspects impact participation in meaningful occupations that promote well-being (Hocking, 2017).

Occupational marginalization: On the basis of discrimination, when individuals are only able to access inferior occupational opportunities or resources, they experience occupational marginalization (jlucido93, 2013, as cited in Hocking, 2017).

Occupational apartheid: "The systematic segregation of groups of people and deliberately denying them access to occupations such as quality education or well-paid work, or occupational contexts, based on prejudice about their capacities or entitlement to the benefits of culturally valued occupations" (Wilcock & Hocking, 2015, as cited in Hocking, 2017, p. 33).

Occupational therapy (OT): "The therapeutic use of everyday life occupations with persons, groups, or populations (e.g., the client) for the purpose of enhancing or enabling participation" (AOTA, 2020a, p. 1).

Occupational therapy (OT) practitioners: Refers to both occupational therapists and occupational therapy assistants (AOTA, 2020a).

Primary health care: "A whole-of-society approach to health and well-being centered on the needs and preferences of individuals, families, and communities" (WHO, 2020c, para.1).

Social determinants of health (SDOH): Conditions in the environments in which people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks (Healthy People, 2020a, para. 5).

Chapter Two: Literature Review

Chronic Conditions

Chronic diseases were defined as "conditions that last one year or more and require ongoing medical attention or limit activities of daily living or both" (CDC, 2020b, para. 1). The CDC listed heart disease, cancer, and diabetes as major chronic conditions, and additionally, substance use and addiction disorders, mental illnesses, dementia and other cognitive impairment disorders, and developmental disorders are considered chronic conditions (CDC, 2020b; U.S. Department of Health and Human Services, 2010). Although discussions of chronic conditions often emphasized their physical impacts, it is essential to also consider co-occurrences of mental health conditions and their impacts.

Mental health.

It was estimated that one-third of individuals who have a chronic condition also experience depressive symptoms (Cleveland Clinic, 2020). Some neurological chronic conditions, such as strokes, cause changes in the brain that can result in depression (NIMH, n.d.). Depression can also occur as a side effect of medications treating the chronic condition or from simply experiencing and adapting to the condition itself (Cleveland Clinic, 2020). Symptoms of depression can include a loss of pleasure in previously enjoyed activities, fatigue, difficulty sleeping, and eating too much or not enough (NIMH, n.d.). Therefore, awareness of the mind-body connection is essential to the well-being of those with chronic conditions.

Anxiety and stress related to managing and adapting to a chronic condition can worsen physical symptoms (Cleveland Clinic, 2020). Similarly, individuals with depression were at a higher risk for certain chronic conditions and developing worsening

of chronic conditions because depressive symptoms can make caring for oneself more taxing, particularly eating healthy foods, taking medication, and staying physically active (Cleveland Clinic, 2020). This cause-and-effect nature of chronic conditions was described by the Cleveland Clinic as a "vicious cycle" between poor mental health status and aggravated physical chronic illness (2020, para. 10).

Multimorbidity.

According to recent statistics, multimorbidity was especially prevalent among older adults, as three out of four U.S. individuals aged 65 years or older had multiple chronic conditions (U.S. Department of Health and Human Services, 2016). Negative health outcomes associated with chronic conditions were compounded by multimorbidity. For instance, additional chronic conditions imply additional hospitalizations, incidents of mortality that could have been avoided, and overall decreased daily functioning (U.S. Department of Health and Human Services, 2016).

One study in particular investigated the complex health needs of those with multiple chronic conditions (MCCs) by interviewing 41 older adults with MCCs, 47 caregivers of adults with MCCs, and 42 providers of adults with MCCs. (Ploeg et al., 2017). Results of this study highlighted the complexity of physical and mental chronic conditions, particularly the evolution of multiple chronic conditions (Ploeg et al., 2017). Across all three groups interviewed, participants described feelings of being "overwhelmed" and "drained" by the level of care for adults with MCCs (Ploeg et al, 2017, p. 7). Participants also described, among many other frustrations, a fragmented healthcare system, the burden of organizing medications and scheduling appointments, and the importance of relying on family members and friends as caregivers (Ploeg et al.,

2017). In order to fully appreciate the effects of chronic conditions, however, their impacts on daily life must also be explored.

Impacts of Chronic Conditions

Previous research suggested the impacts of chronic conditions were significant—both at the system and individual levels. In 2019, chronic conditions were the leading causes of death and disability in the U.S. and the primary contributors to the nation's $3.5 trillion spending on annual health care costs (CDC, 2020a). According to 2016 data, healthcare costs associated with multiple chronic conditions were responsible for 66% of total health care spending (U.S. Department of Health & Human Services). Perhaps more concerning to healthcare providers, however, are the individual physical, emotional, and social challenges associated with chronic conditions.

Occupational participation.

Chronic conditions affected various areas of life, including participation in valued daily activities, responsibilities, and social relationships (AOTA, 2015; Buttorff, Ruder & Bauman, 2014). Specifically, those with chronic conditions often experienced functional limitations, such as a decreased ability to perform Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs) (Cameron, 2019; Buttorff et al., 2014). Due to these limitations, individuals with chronic conditions had an increased need for medical supports and caregivers (Cameron, 2019).

Furthermore, individuals with chronic conditions experienced stress associated with a decreased ability to work or unemployment (Cleveland Clinic, 2020). Wang, Wang and Halliday (2018) compared data from the Panel Study of Income Dynamics (PSID) before and following the Great Recession of 2007-2009 and found that

unemployment rates were linked to significant declines in physical and mental health. Therefore, chronic conditions can result in additional stress and, alternatively, stress can bring about poor physical and mental health. In addition to personal physical and mental factors, poor social and environmental conditions contributed to the development and worsening of chronic conditions (Shaw, Theis, Self-Brown, Roblin & Barker, 2016; Pinter-Wollman, Jelic & Wells, 2018).

Social Determinants of Health

Poor health outcomes for this population can arise from, or be exacerbated by SDOH, broadly known as the everyday environmental conditions that impact health (Healthy People, 2020a). Examples of SDOH include social support, access to health care, safe housing and food resources, access to educational and employment opportunities, presence of crime and poor living conditions, social norms and views, socioeconomic status, access to media, culture, health literacy, and language barriers that impact health status (Healthy People, 2020a).

Felner, Dudley, and Ramirez-Valles (2018) explored the effects of several compounding SDOH, including race, socioeconomic status, and LGBTQ+ status. Researchers obtained qualitative data from a focus group with 26 LGBTQ+ YOC (Youth of Color) living in the South and West sides of Chicago. Participants expressed that they were often turned away from LGBTQ+ centers in predominantly white, middle class areas because they were racially profiled and assumed to reside in the lower-income and higher crime South and West sides (Felner et al., 2018). As a result of racial discrimination, participants experienced decreased access to social support and health-related services (Felner et al., 2018).

Additionally, individuals can experience physical determinants of health, such as the natural and built environment, lack of access to physical structures for those with disabilities (e.g. lack of ramps, elevators), poor environmental conditions, housing and community design, and daily work settings (Healthy People, 2020a). As Pinter-Wollman and colleagues (2018) concluded, the built environment has a central role in preventing and managing chronic conditions. For example, the availability of safely walkable destinations in residential communities either promoted or hindered daily physical activity (Pinter-Wollman et al., 2018). Moreover, access to a healthy diet was often dependent on the geographic availability of grocery stores. The built environment can even impact mental health, particularly in terms of housing quality, access to green space, and crowded conditions in urban settings (Wells & Harris, 2007; Pinter-Wollman et al., 2018; Evans, Lepore & Schroeder, 1996).

The impact of SDOH in terms of the development or worsening of chronic conditions has been widely accepted based on available literature (Shaw et al., 2016; Shin, Kwon & Shaban-Nejad, 2019). Shaw and colleagues (2016) utilized 2013 Behavioral Risk Factor Surveillance System (BRFSS) data, a randomized survey for adults at least 18 years old, to determine the relationship between socio-economic status and the prevalence of chronic conditions. A total of 448,790 participants from 3,064 U.S. counties responded to the survey. Based on the self-reported survey results, even after the data was adjusted for individual health risk factors, poor health and higher mortality rates were associated with area-level poverty (Shaw et al., 2016). Specifically, the presence of hypertension, arthritis, and general poor health was 9%, 13%, and 15% higher, respectively, than in the most affluent counties included in the study (Shaw et al., 2016).

More recently, a 2019 study concluded that the presence of multiple chronic conditions was associated with poor socio-economic conditions, such as crime, severe poverty, and high unemployment rates (Shin et al., 2019).

In summary, factors such as race and ethnicity, socioeconomic status, age, sex, sexual orientation, gender identity, and residential location continue to lead to variable access to care for Americans (Agency for Healthcare Research and Quality, 2018). The impacts of SDOH have also been observed specifically in the chronic condition population (Shaw et al., 2016; Sin at al., 2019). In turn, social, political, economic, and environmental inequities resulted in health disparities (CDC, 2018).

Health Disparities

Health disparities were defined by the CDC in 2018 as disease, injury, violence, or overall poor health that disproportionately impacts socially disadvantaged populations. Health disparities were widely recognized by several U.S. government agencies and well-supported by research. For example, the National Healthcare Quality and Disparities Report, last conducted in 2018, is a U.S. Congressional requirement that summarizes healthcare disparities for different racial and socioeconomic populations (Agency for Healthcare Research and Quality, 2018). Outcomes related to quality of healthcare received were grouped by person-centered care, patient safety, healthy living, effective treatment, care coordination, and care affordability. In terms of racial and ethnic disparities, African-Americans, American Indians, Alaska Natives, and Native Hawaiians/Pacific Islanders received worse care than Caucasians for about 40% of quality measures and Hispanics received worse care than Caucasians for 35% of quality measures (Agency for Healthcare Research and Quality, 2018). Finally, Asians received

worse care than Caucasians for about 27% of quality measures but better care than Caucasians 28% of quality measures (Agency for Healthcare Research and Quality, 2018).

Furthermore, low socioeconomic status (SES) was associated with poor health outcomes, and therefore contributed to health disparities (Healthy People, 2020b; Lago et al., 2017). The results of a study using computer simulation indicated that low SES was significantly associated with early coronary heart disease (CHD) for about 25% of U.S adults 35-64 years old (Hamad et al., 2020). A similar study analyzing five nationally representative data sources suggested that individuals with the lowest levels of education and the lowest SES experienced worse health (Braveman, Cubbin, Ergerter, Williams & Pamuk, 2010). Also, for all ethnicities except for White, individuals at 100% below the federal poverty level (FPL) made up the highest percentage of those with diabetes, as compared to those at 100-199% FPL, 200-299% FPL, 300-399% FPL, and greater than or equal to 400% FPL (Braveman et al., 2010). Given the clear presence of health disparities across different socially disadvantaged populations, literature examining the causes of health disparities informed healthcare intervention.

Graham (2015) suggested provider, individual, and systems-level factors have contributed to health disparities. First, providers may have had decreased cultural competency, or even held unconscious biases, that impacted care. A systematic review of 37 studies confirmed that most healthcare providers had implicit biases against Black, Hispanic, American-Indian, and dark-skinned individuals (Maina, Belton, Ginzberg, Sing & Johnson, 2018). However, the long-term impacts of these biases were not known, as

there was limited research regarding how they relate to health outcomes (Maina et al., 2018).

Providers who are culturally competent have an active role in combating health disparities. The results of a study in 2013 that examined primary care provider cultural competence and disparities in HIV care and outcomes indicated that racial disparities may be reduced by improving provider cultural competence (Saha et al., 2013). Patient-centered care, characterized by good communication between the client and provider, led to improved health outcomes (Weiner et al., 2013), including improved health status (Agency for Healthcare Research and Quality, 2018). However, according to the Agency for Healthcare Research and Quality (2018), language barriers, racial and ethnic differences between client and provider, and provider cultural competency were factors contributing to poor provider-client communication.

Individual behaviors and decisions also influenced health outcomes, especially in terms of the development and/or worsening of chronic conditions. As stated by several government health agencies, risk behaviors such as tobacco use, poor nutrition, and lack of physical activity can lead to chronic conditions (CDC, 2020b; WHO, 2020a). However, it is important to acknowledge the role external factors played in decision-making regarding health. Xiao, Berrigan, and Mattews (2017) concluded that poor health was associated with living in low SES neighborhoods for individuals with various types of cancers and could be correlated to the outcome of several factors. For example, dietary choices for individuals in low SES communities could have been limited due to the scarcity of grocery stores and restaurants with a wide selection of healthy choices (Hilmers, Hilmers & Dave, 2012). Moreover, neighborhoods with high crime rates may

have induced chronic stress for individuals that live in these communities, which impacted decision-making regarding health (Chen & Miller, 2013; Miller, Chen & Parker, 2011). Therefore, individual health behaviors were subjected to systemic supports and barriers.

At the broader systems level, elements of the current healthcare system have contributed to health disparities. Americans have historically received variant access to care as determined by race and ethnicity, socioeconomic status, age, sex, disability status, sexual orientation, gender identity, and residential location (Agency for Healthcare Research and Quality, 2018). Limited access to care was partially due to lack of insurance coverage, which is disproportionately experienced by socially disadvantaged groups. This was due, in part, to decreased employment and marriage opportunities for minority groups, both of which are associated with access to health insurance coverage (Sohn, 2017). Therefore, African American and Hispanic populations were more likely to suffer greater losses of insurance and slower insurance gain (Sohn, 2017). Similarly, the 2011 Marriage Equality Act that allowed the licensure of same-sex marriage in New York, highlighted the association between legalized same-sex marriage and health insurance coverage (Sohn, 2017). A study analyzed data from the 2008-2012 American Community Survey and found that New York's 2011 Marriage Equality Act was associated with a significant increase in employer-sponsored health insurance (Gonzales, 2015).

Collective research has demonstrated that disparities in lack of access to care were particularly of concern for individuals with chronic conditions. Shi, Chen, Nie, Zhu, and Hu (2014) examined racial and economic disparities for individuals with chronic

conditions in terms of access to primary care services. Results indicated minority groups were less likely to have a Usual Source of Care (USC), a key aspect of medical attention for individuals with chronic conditions due to consistent healthcare needs. Furthermore, minority groups were more likely to list a USC as a hospital or similar facility, rather than a specific doctor or doctor's office (Shi et al., 2014).

While health disparities are not a recent phenomenon, they remain a significant threat to health equity in the current U.S. healthcare system (Agency for Healthcare Research and Quality, 2018). Although some progress has been made to mitigate health disparities, they have remained persistent in terms of access to healthcare, particularly for poor and uninsured populations (Agency for Healthcare Research and Quality, 2018). Not only are OT practitioners prepared to address issues related to health disparities, AOTA (2013) asserted that OT practitioners have an obligation to address health inequities at the individual, community, and population levels.

An Issue of Occupational Justice

Practitioners can only address health inequities by first acknowledging instances of occupational injustice, when social conditions give rise to inequities in accessing or participating in healthful occupations across different groups of people, where some benefit and others experience occupations that are harmful to their health and well-being (Hocking, 2017). Occupational injustice can result from either engaging in occupations that are harmful or the inability to participate in valued, health-promoting occupations (Hocking, 2017). Importantly, occupational injustice can stem from discrimination when individuals experience *occupational marginalization* or larger-scale prejudices resulting in *occupational apartheid*.

The concept of occupational injustice was illustrated by a study examining the impact of unsafe water on occupational participation (Blakeney & Marshall, 2009). Due to coal mining practices in Letcher County, Kentucky, local residents experienced widespread unsafe water quality and, therefore, limited participation in valued occupations. Not only were residents deprived of engaging in valued leisure activities, such as fishing, tubing, swimming, they were forced to take additional measures to protect their health. Many residents identified purchasing cleaning supplies, various water filters, and bottled water to adapt to the poor water quality in their area. Discolored clothing and home appliances also resulted from their polluted water supply and significantly impacted the self-esteem and mental health of residents. Blakeney and Marshall (2009) illustrated how poor water quality led to engaging in occupations that were potentially hazardous to the health of the residents. Another type of occupational injustice, called *occupational deprivation,* was experienced by the residents, as external aspects impacted participation in meaningful occupations that promote well-being, such as fishing and socializing with community members (Blakeney & Marshall, 2009; Hocking, 2017).

According to the Philosophical Base of Occupational Therapy, participation in meaningful activities impacts health and well-being and, “thus, participation in meaningful occupations is a determinant of health and leads to adaptation” (AOTA, 2017, p. 1). Prior literature has documented the physical and mental implications of chronic conditions (Cleveland Clinic, 2020; NIMH, n.d.; CDC, 2020b; U.S. Department of Health and Human Services, 2010). Moreover, the presence of multiple chronic conditions was shown to further exacerbate poor health and well-being, including

increased risk of hospitalization (U.S. Department of Health and Human Services, 2016). Previous studies have also demonstrated that disproportionately experienced SDOH and resulting health disparities worsened the effects of chronic conditions (Pinter-Wollman et al., 2018; Shaw et al., 2016; Shin et al., 2019; Hamad et al., 2020, Braveman et al., 2010; Shi et al., 2014). Therefore, individuals who have a chronic condition(s) or are at risk for developing them can experience occupational injustice and would benefit from OT intervention.

Primary Care

The WHO (2020c) described primary health care as "a whole-of-society approach to health and well-being centered on the needs and preferences of individuals, families, and communities" (para. 2). Therefore, community-based settings that provide primary care services were an integral access point for those impacted by chronic conditions prior to requiring hospitalization or long-term care. While this healthcare model was essential for individuals with chronic conditions or those who are at risk for developing chronic conditions, their needs were not always met by the current system (Leland et al., 2017).

The role of OT in primary care.

Waite (2014) described OT practitioners as valuable team members, a trait that is essential within the primary care setting. OT practitioners were well-equipped to address patient care coordination, chronic disease management, home- and community-based services, and mental and behavioral health services, all of which are ideal aspects of the primary care model (Waite, 2014). From educating providers on the importance of recommendations that can be sustained in the client's daily routine, to addressing cognitive and psychological contributions to non-adherence, and even coordinating care

by sharing client's home environments and occupational profiles with other providers, OT practitioners were effective in the primary care setting (Waite, 2014). One of the most valuable roles of OT practitioners in primary care, however, was assisting primary care providers with increasing time demands.

Prior research has documented the ongoing medical care and resulting long-term functional limitations associated with chronic conditions, as opposed to acute, short-term conditions (Stern, 2019). However, despite the complex needs associated with chronic conditions, professionals in primary health care settings have continued to face rising challenges to meet them due to time constraints (Winship, Ivy & Etz, 2019). According to data from an online survey, most physicians saw 11-20 patients per day and only 11% of physicians surveyed spent 25 minutes or more with their patients (Elflein, 2019). As a result, primary care providers often referred to other professionals for more specific patient needs, such as mental health and musculoskeletal concerns, that could have been met by an OT practitioner serving as a member of the primary care team (Dahl-Popolizio, Manson, Muir & Rogers, 2016; Muir, 2012). Therefore, delegating patient needs to OT practitioners in primary care decreased siloed care, increased access to care, and allowed primary care providers more time to see other patients (Altschuler, Margolius, Bodenheimer & Grumbach, 2012).

Not only could OT practitioners assist in mitigating time constraints, they had the distinct position of helping clients to recognize barriers to optimal health and assisting in implementing health behavior changes (Dahl-Poplizio et al., 2016). As stated by several government health agencies, chronic conditions were attributed to certain health risk behaviors, including tobacco use and second-hand smoke, poor nutrition, and lack of

physical activity (CDC, 2020b; WHO, 2020a). OT practitioners can evaluate these lifestyle choices, whether they pose as a barrier to the client's health and implement behavior modification strategies that can be integrated into daily routines (Dahl-Popolizio et al., 2016).

Dahl-Popolizio and colleagues (2016) also discussed specific medical, rehabilitative, and behavioral health issues that could be addressed by OT practitioners in primary care settings. In terms of chronic conditions such as diabetes, cardiac diseases, and hypertension, OT practitioners could provide intervention for medication management and other self-management strategies, developing routines and habits to promote dietary changes and adherence, and activity programs targeting goals and incorporating individual interests (Dahl-Popolizio et al., 2016). Additionally, OT practitioners addressed co-occurrences of depression and anxiety, provided coping strategies, helped clients adjust to their illness, educated clients regarding community resources, and educated family members on how to support the client (Dahl-Poplizio et al., 2016). Co-occurrences of chronic conditions, or multimorbidity, has also been addressed by OT practitioners in community-based settings. For example, a six-week long OT-led self-management program was shown to improve frequency and performance of activity participation, self-efficacy, quality of life, and independence in daily activities for individuals with multiple chronic conditions (Garvey, Connolly, Boland & Smith, 2015).

Perhaps most importantly, OT as a profession strives to be client-centered by considering the client's environment, values, goals, and the transactional relationship between mind, body, and spirit (AOTA, 2020a). However, older adults with MCCs and

caregivers for adults with MCCs recalled that providers in primary care settings focused on only one condition or part of their health, rather than considering them as a whole person (Ploeg et al., 2017). Older adults with MCCs and caregivers alike described "being split into pieces" and detailed the lack of coordination in their care (Ploeg et al., 2017, p. 8). OT practitioners can offer a unique viewpoint in care for adults with multiple chronic conditions, as they consider the impact of the client's environment, interactions of mind, body and spirit, and most importantly, see the client as a whole being (AOTA, 2020a).

The skillset of OT practitioners complements that of primary care providers. Furthermore, previous literature has established the role of OT practitioners in preventing and managing chronic conditions in primary care settings (Leland et al., 2017; Dahl-Popolizio et al., 2016; Altschuler et al., 2012; Muir, 2012). By filling gaps in current primary care services, considering the client's overall context, and acknowledging the impact of mental health when addressing chronic conditions, OT practitioners have distinct value as members of the primary care team.

Intervention strategies.

Defined as the "process of enabling people to increase control over, and to improve their health," health promotion practices included preventing the development and progression of disease (AOTA, 2020b, p.1). Addressing health promotion was a prerequisite to successful OT intervention in primary care settings (Jordan, 2019). Health management was another tool that can be used by OT practitioners in the primary care setting for those with, or at risk for, chronic conditions.

Health management was founded in empowering individuals to take control of their own health (AOTA, 2015). Rather than just identifying and remediating hazardous behaviors, OT practitioners assisted in building sustainable health management skills into existing routines for those with chronic conditions (AOTA, 2015). Health management includes social and emotional health promotion and maintenance, symptom and condition management, communication with the health care system, medication management, physical activity, nutrition management, and personal care device management (AOTA, 2020a).

Lifestyle Redesign.

Lifestyle Redesign is an OT intervention that facilitates health-promoting and valued routines and habits to help clients realize health goals related to physical, mental, cognitive, and emotional health (University of Southern California, n.d.). Specifically, Lifestyle Redesign was designed to help clients acknowledge their unique valued occupations and the opportunity for sustained positive change (Jackson, Carlson, Mandel, Zemke & Clark, 1998). The efficacy of Lifestyle Redesign in community-based, preventive OT intervention was first examined in The Well Elderly study.

Conducted from 1994 to 1996, the Well Elderly study included adults aged 60 or older living independently in the Los Angeles area (Jackson et al., 1998). Participants either received preventive OT intervention, social activities led by non-healthcare professionals, or no intervention at all. The OT intervention consisted of group educational sessions focusing on the power of occupations; aging, health, and occupation; transportation; safety; social relationships; cultural awareness and finances. Individualized intervention, including one-on-one time with participants, was allotted to

complete an occupational self-analysis and then create tailored Lifestyle Redesign plans. Participants then carried out these plans by taking risks, such as trialing new transportation or engaging in new social engagement, within safe environments. As a result, participants who received preventive intervention from OT practitioners demonstrated improved or maintained physical health, mental health, physical functioning, social functioning, and vitality (Jackson et al., 1998). While the Well Elderly Study addressed needs of the well population in terms of preventing chronic illness, many studies have investigated the effectiveness of Lifestyle Redesign intervention for those with chronic conditions.

A 2019 study, for example, investigated the effectiveness of a one-year randomized control-trial pilot study of Lifestyle Redesign Occupational Therapy (LR-OT) that addressed diabetes in a safety-net primary care clinic (Pyatak et al., 2019). 155 adult patients with a diagnosis of Type 1 or Type 2 diabetes were randomized to either the LR-OT group or a no-contact comparison group. The LR-OT intervention was based on the REAL Diabetes treatment manual and included mostly individual sessions to formulate and carry out goals, activities, and resources related to managing their condition. Study outcomes included both quantitative survey data as well as qualitative data from interviews and focus groups with providers and clients who participated in the implementation of the LR-OT program. Providers who participated in the study concluded that LR-OT was a good match for the primary care setting and served to address a gap in current services provided (Pyatak et al., 2019). Providers also reported that OT services helped their patients to decrease negative health behaviors and increase positive health behaviors through addressing habits and routines pertaining to diabetes

(Pyatak et al., 2019). Furthermore, as a result of the OT interventions, providers gained a stronger understanding of the scope of OT practice (Pyatak et al, 2019).

Prior literature has also explored Lifestyle Redesign OT intervention for chronic pain, as individuals who experience chronic pain required adaptations to daily habits and lifestyle routines to mitigate barriers to occupational engagement (Uyeshiro Simon & Collins, 2017). Uyeshiro Simon and Collins (2017) recruited 45 patients to participate in an outpatient clinic Lifestyle Redesign intervention as part of their usual medical care. Outcomes related to perceived performance and satisfaction over time, quality of life, perceived pain, and self-efficacy were measured using the Canadian Occupational Performance Measure, 36-Item Short-Form Survey, Brief Pain Inventory (BPI), and Pain Self-Efficacy Questionnaire, respectively. While results of the study did not reveal significant changes to pain intensity levels themselves, participants who engaged in the Lifestyle Redesign intervention demonstrated increased quality of life, self-efficacy, and functional status for those with chronic pain conditions (Uyeshiro Simon & Collins, 2017).

Overall, the effectiveness of Lifestyle Redesign has been established in earlier research, particularly for improving physical, mental, and social outcomes for individuals with chronic conditions (Jackson et al, 1998; Pyatak et al, 2019; Uyeshiro Simon & Collins, 2017). Recent studies have confirmed the continued relevance of health promotion and health management interventions (Pyatak et al., 2019; Uyeshiro Simon & Collins, 2017). Medication management presents another opportunity to OT intervention with this population. Similar to Lifestyle Redesign intervention, interventions for medication management require attention and adaptations to daily habits and routines.

Medication management.

One way that OT practitioners can help individuals to achieve long-term health is by facilitating daily routines to decrease and prevent dysfunction (AOTA, 2015). One common and essential daily routine for individuals with chronic conditions is managing medication regimens. In fact, "organizing pills" was emphasized as a significant component of care by not only adults with MCCs, but also caregivers and providers for this population (Ploeg et al., 2017). Schwartz and Smith (2017) outlined several roles for OT practitioners in medication management intervention for individuals with chronic conditions.

Schwartz and Smith (2017) emphasized that difficulty adhering to medication schedules typically involved aspects of the person, environment, and task and their dynamic interactions. Interventions used by OT practitioners addressed each of these through initiating behavior changes, assimilating medication management into daily routines, using assistive technology, helping the client to self-monitor symptoms, providing the client with education, and focusing on behavioral impacts such as provider-patient interactions (Schwartz & Smith, 2017). Specifically, OT practitioners reinforced medication management by focusing on the causes of nonadherence. Examples included addressing health literacy concerns and physical barriers, such as fine motor skills required to open a pill bottle, that prevented following through with medication recommendations (Schwartz & Smith, 2017). Medication management was key, as clients who were not adherent to medication protocols had worse overall experiences in the healthcare system, contributing to poor health outcomes at the population level (Schwartz & Smith, 2017). However, implementation of medication management

strategies served to increase client adherence to medication protocols, and therefore prevent future hospitalization or admission to long-term care facilities (Schwartz & Smith, 2017).

One study in particular investigated the effectiveness of OT interventions for medication management to address the needs of individuals with chronic conditions. Schwartz and colleagues (2017) recruited 19 adults with chronic conditions and poor medication adherence to participate in a randomized control trial. Participants were randomized either to the Occupational Therapy Intervention Group (OTIG) or Standard Care Intervention Group (SCIG). The OTIG was administered the Integrative Medication Self-Management Intervention (IMedS), a manualized, three-step intervention in which participants first discussed prior medication management history and then set goals related to medication adherence. Then, clients were assisted in developing strategies to achieve the determined goal, such as altering the activity itself, advocacy, education, assistive technology, environmental modifications, and securing timely refills (Schwartz et al., 2017). Following the intervention, over half (55%) of OTIG participants reported increased medication management, as compared to only 30% of the SCIG participants (Schwartz et al., 2017). While participants in the SCIG demonstrated decreased medication adherence and only identified four types of strategies used, medication adherence of participants in the OTIG was maintained and they were able to identify eight types of strategies (Schwartz et al., 2017).

Lifestyle Redesign and medication management, interventions previously examined in OT literature, were especially effective for individuals with chronic conditions. However, future research is needed to further support the efficacy of OT

interventions for individuals with chronic conditions in primary care settings. The setting for the current study, the Ithaca Free Clinic, has a Chronic Care Program and established OT services, and thus presented an opportunity to examine the needs of the local community in terms of health promotion and health management interventions provided by OT practitioners.

The Ithaca Free Clinic

The Ithaca Free Clinic (IFC), located in downtown Ithaca, New York, is a community-based primary care clinic that offers free medical and multiple complementary and integrative health services for un- and under-insured adults in Tompkins County. These services aim to "create a sustainable model of community-oriented, community-driven solutions to the ongoing healthcare crisis" and meet the needs of those who are underserved by the traditional healthcare system (Ithaca Free Clinic, n.d.., para. 2). From walk-in appointments for acute needs, to integrative and complementary health services, clients of the IFC have a diverse set of health needs.

Clients may be seen by appointment during walk-in clinic hours twice a week for acute, primary care issues. The IFC provides services offered by volunteer providers, including occupational therapy, Western Herbal Medicine, acupuncture, massage therapy, chiropractic care, women's health/gynecology, nutrition consultation, energy work, and Reiki services (Ithaca Free Clinic, n.d.). Counselors are also available during walk-in hours to assist individuals and families in applying for public health insurance. Available services vary depending on the availability of the providers.

The IFC also has several partnerships that reinforce community support for clients and hosts community-based events that are free and open to the general public, such as a

weekly Food Pharmacy, free mammogram checks, and monthly optometry checks (Ithaca Free Clinic, n.d.). The IFC also partners with organizations in the local community, such as Planned Parenthood, the Advocacy Center, Cayuga Health System, the Southern Tier AIDS Program, Tompkins County Mental Health Department, and others (Ithaca Free Clinic, n.d.). Educational partners, such as Ithaca College, New York Chiropractic College (NYCC), and Cornell University, collaborate to develop learning experiences where professional students provide discipline specific services at the IFC.

The Ithaca College Department of Occupational Therapy began its partnership with the IFC in 2008. Through this partnership, OT students provide free therapy services to clients of the IFC one day per week under the supervision of a licensed OT faculty member. The overall purpose of OT services at the IFC is to help people who are experiencing occupational challenges to achieve positive health outcomes through engagement in meaningful occupations (Ithaca Free Clinic, n.d.).

The Chronic Care Program generally helps clients with chronic conditions set goals for their long-term health and offers support in achieving these goals (Ithaca Free Clinic, n.d.). This is accomplished by providing clients who have chronic conditions with regular appointments at the IFC (Ithaca Free Clinic, n.d.). An integrated approach is utilized by health and administrative professionals within the Chronic Care Program to meet the often-complex needs of clients with chronic conditions. After an initial evaluation for health issues and goal areas, clients are offered the many healthcare options to choose from, such as acupuncture, chiropractic care, massage, counseling, herbal medicine, dieticians, energy work, and occupational therapy.

While clients are sometimes referred to and select OT services following the initial evaluation for the Chronic Care Program, it is common for providers to also make additional referrals to OT if they recognize the need for OT services after their initial evaluation or at any time throughout treatment. Providers typically refer clients to OT for an array of different reasons, such as self-care and IADL needs, strength, sensation, range of motion, neurological issues, return to work, pain management, coordination, cognition, mental health issues, and others (AOTA, 2020a).

In an initial meeting with the Director of Chronic Care, it was reported that OT services are underutilized by clients, both generally at the IFC and in the Chronic Care Program. The Director of Chronic Care explained that this was possibly due to a lack of representation of OT at initial triage meetings in which clients with a diagnosed chronic condition(s) are referred for services. Also, it was reported that some clients who are referred to OT services may not see the value of OT, and therefore do not make an appointment. Even if clients agree that they would benefit from OT, certain barriers may prevent them from following through with attending scheduled appointments (e.g. childcare, transportation, time, appointment availability, etc.). Therefore, a major focus of the study was to determine possible barriers to participating in OT services, how they relate to clients' health beliefs and environmental circumstances, and to describe the need for OT services that address the prevention and management of chronic conditions at the IFC. This study also examined the factors that lead to clients being referred to OT at the IFC, including providers' understanding of the scope of OT.

Models to Guide the Study

The Health Belief Model.

The Health Belief Model (HBM) describes six tenants explaining why people make certain decisions about their health (National Cancer Institute, 2005). Specifically, these six tenants categorize people's decisions about whether to take action to prevent, screen for, and control illness. The tenants outlined in the HBM include perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action and self-efficacy (National Cancer Institute, 2005).

First, *perceived susceptibility* includes beliefs about one's likelihood of getting a condition. Next, *perceived severity* is an individual's beliefs about the seriousness and consequences of a condition. *Perceived benefits* are what the person believes they have to gain from health intervention. Therefore, individuals who do not appreciate the perceived benefits of taking action to reduce the risk for a serious condition would benefit from education on potential positives of taking action and how, where, and when to take action (National Cancer Institute, 2005).

Perceived barriers are an individual's beliefs about the material and psychological costs of taking action. The *cues to action* tenant is how ready a person is to make health changes, and the *self-efficacy* tenant is one's confidence in their ability to take action for their health (National Cancer Institute, 2005). According to the HBM, if individuals have a diagnosed condition that is asymptomatic, they are often less willing to adhere to medication protocols and physician recommendations (National Cancer Institute, 2005). Similarly, individuals may think taking action or taking preventive measures for their health is unnecessary if they are at risk for, but do not yet have, a chronic condition, and therefore not take preventative measures.

In this study, the HBM was used as a guide to develop the survey and gather information from clients of the IFC. It was important to gain a general understanding of clients' health beliefs, as incorporating this knowledge into OT intervention serves to increase adherence, build rapport, and maintain client-centered care. The tenets of perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action and self-efficacy were each represented by a survey question.

The Person-Environment-Occupation Model.

Although individual beliefs play a role in health outcomes, health decisions are made within an individual's overall context, and so environmental aspects were also considered in this study. Specifically, clients' social and physical environments served to either facilitate or hinder their participation in OT services at the IFC. Therefore, the Person-Environment-Occupation (PEO) Model was used as an additional framework for this study.

Dynamic interactions between the environment, the person, and the occupations they engage in were emphasized by the PEO Model (Law et al., 1986). The *person* was defined as a unique individual who occupies different roles simultaneously. The PEO Model also posited that the person is holistic and must be considered in terms of mind, body and spirit. Next, the *environment* served either as a support or barrier to occupational performance, and included the cultural, socio-economic, institutional, physical and social environments. Finally, *occupations* were defined as "groups of self-directed, functional tasks and activities in which a person engages over the lifespan" (Law et al., 1986, p. 16) Occupations met intrinsic needs and were completed with a sense of purpose (Law et al., 1986).

As described in the PEO Model, the person, environment, and occupation engage in a transactive relationship, where one cannot be separated from the other. For example, the PEO Model asserted that the environment both influences, and is influenced by, individual behavior. When there exists a good fit between the person, environment, and occupation, there is greater opportunity for *occupational performance*, or "the dynamic experience of a person engaged in purposeful activities and tasks within an environment" (Law et al., 1986, p. 17). Most importantly, the PEO Model stated that the environment is not stagnant and, likewise, individuals are constantly adapting to new circumstances (Law et al., 1986).

Concepts explored in the PEO Model and contributing literature provided insight for the current study. It was clear that the complexity of chronic conditions was due, in part, to the dynamic interactions of the person, environment, and occupations in which they engage. Therefore, for the purposes of this study, clients must be viewed not only as individuals, but as groups of people within an overall system, some of which were disproportionately impacted by social determinants of health.

Summary

Not only do chronic conditions place a heavy burden on the U.S. healthcare system, the physical, mental, and emotional symptoms of chronic conditions impact various aspects of everyday life (CDC, 2020a; AOTA, 2015). While individuals with chronic physical conditions are considered to be at an increased risk for developing chronic mental conditions, the reverse is also true—the presence of mental illness, such as depression, can lead to or exacerbate chronic conditions (Cleveland Clinic, 2020). Multimorbidity added to the complexity of chronic conditions, as the presence of more

than one chronic condition can further increase the risk of hospitalization and mortality (U.S. Department of Health and Human Services, 2016). Furthermore, the physical and social environment can give rise to and/or worsen chronic conditions and lead to health disparities (Shaw et al., 2016; Shin et al., 2019).

OT practitioners can facilitate participation in meaningful activities by providing intervention related to prevention, lifestyle modification, and physical and psychosocial rehabilitation for individuals with chronic conditions (AOTA, 2015). The HBM and PEO Model were used as frameworks for the current study to consider the contribution of both personal beliefs and environmental impacts to the prevention and management of chronic conditions. This study aimed to determine the needs of clients at the IFC in terms of OT services for the prevention and management of chronic conditions, supports and barriers to participation in OT services, and supports and barriers to referring to OT services.

Chapter Three: Methods

Subjects

Data was collected from clients and providers at the Ithaca Free Clinic (IFC), a free local community-based clinic that offers primary care services. The study was approved by the Ithaca College Institutional Review Board (IRB) on November 26th, 2019 (Appendix A).

Clients.

To participate in this study, clients were required to be a current client of the IFC and at least 18 years old. Former clients of the IFC who were not currently seeking treatment were excluded from the study.

Recruitment.

Clients were recruited to participate in an online anonymous survey while waiting to see a provider during walk-in clinic hours at the IFC. Clients could participate in the survey by scanning a QR code linked to the survey on a flyer in the waiting room. Alternatively, clients could complete the survey using Ithaca College Department of Occupational Therapy iPads. Using a script, the primary investigator (PI) facilitated participation through use of the iPads for while in the waiting room for 35 hours over ten days. As an incentive to complete the survey, clients were informed of the opportunity to enter a drawing to win one of four $25 grocery store gift cards. Refer to Appendix B for the poster advertising the survey and Appendix C for the recruitment script used by the PI.

Providers.

Providers were required to be currently volunteering their services at the IFC and at least 18 years of age to participate in this study. Former providers who were not currently providing services at the IFC, administrative staff and other non-clinical staff, such as the receptionist and director, were excluded from this study. Occupational therapy providers at the IFC were also excluded from this study.

Recruitment.

The Director of Chronic Care assisted in the recruitment of providers by compiling a list of all providers currently working at the IFC and their e-mail addresses. The PI e-mailed the providers on December 23, 2019 with a brief description of the study and a link to the online survey. The PI sent one follow up reminder email on January 15, 2020, to promote increased participation. The survey was open for a total of 5 weeks. Appendix D includes the recruitment e-mail sent to providers.

Research Design

A mixed-methods, descriptive study design was utilized to gain input from both clients and providers at the IFC. To achieve this, both quantitative and qualitative data were gathered using a combination of multiple choice, yes/no, and open-ended question formats.

Measurement Tool

A total of three surveys were created using the online Qualtrics survey platform (Qualtrics, 2020). The *Provider Survey* collected data from providers volunteering their services at the IFC and the *Client Survey* collected data from clients attending walk-in clinic hours at the IFC. The *Client Gift Card Entry Survey* collected the client's name and contact information for the chance to win a grocery store gift card. The Provider Survey

and the Client Survey collected quantitative data with multiple choice and yes/no questions. Clients and providers were asked to rate their level of agreement with various statements using a Likert scale with strongly agree, agree, disagree, and strongly disagree options. Open-ended survey questions on the Provider Survey and Client Survey were used to collect qualitative data. The online surveys were each designed to take 5-10 minutes to complete and all participants could skip any questions or exit the survey without penalty. The Occupational Therapy Practice Framework 4th edition (OTPF-4) and the Health Belief Model (HBM) were used as references for the client and provider surveys. The occupations in Table 2 of the OTPF-4 were the basis for the OT service areas listed in the surveys and were written in more accessible language (AOTA, 2020a).

Client Survey.

The Client Survey consisted of four sections—a demographic section, a section with prompts based on tenants of the HBM, a section listing various OT service areas, and a section of open-ended questions. In the demographic section, clients reported their age and gender and indicated whether they have a caregiver for themselves or if they are a caregiver for a family member or close friend. This section also provided clients with a brief definition of chronic conditions and asked whether or not they had one or more chronic conditions. If clients indicated having one or more chronic condition(s), they then reported how the condition(s) impacts their daily life with an open-ended response.

Next on the Client Survey was a section regarding the HBM. Here, clients indicated their level of agreement with tenants of the HBM using the same Likert scale. Each statement corresponded to either perceived susceptibility, perceived severity, perceived

benefits, perceived barriers, cues to action, or self-efficacy related to their management of, or risk for developing, a chronic condition (National Cancer Institute, 2005).

The third section of the Client Survey included a brief description of OT to give clients context for various OT service areas to address the prevention and management of chronic conditions. For each OT service area, clients used the same Likert scale, indicating how much they agree they would benefit from the service area. The OT service areas were based on occupations listed in Table 2 of the OTPF 4 (AOTA, 2020a). A few examples of OT service areas included managing daily medications and navigating the healthcare system. Refer to the Client Survey instrument for the full list of OT service areas (Appendix E).

Lastly, in the fourth section of the Client Survey, clients responded to open-ended questions about their perspectives of the word "health" as well as barriers and supports to accessing OT services at the IFC. The open-ended questions were intended to glean more in-depth information and gave clients the opportunity to respond using their own wording. The Client Survey is located in Appendix E and the Client Gift Card Entry Survey is located in Appendix F.

Provider Survey.

The Provider Survey included three sections. The first section collected general information such as providers' role at the IFC, their years of experience at the IFC, and referrals made to OT services. The second section listed various OT service areas and the third section consisted of open-ended questions.

In the first section, providers indicated their role at the IFC (e.g. Nurse/Nurse Practitioner, Acupuncture, Chiropractor, Physician (MD), Massage Therapist, Women's

Health, Nutrition or "other"). Then providers selected their years of experience volunteering their services at the IFC. Providers next reported whether or not they had referred a client(s) to OT in the past and the reason for the referral. They could select one or more reasons for referral including Activities of Daily Living (ADL) skills, strength, range of motion, coordination, neurological issues, pain management, cognition, return to work, higher level ADL skills, mental health issues, sensation, and/or "other".

The second section of the Provider Survey included a brief description of OT and the same OT service areas listed on the Client Survey. Here, providers responded to each service area based on how likely they were to refer to OT to address this area. The OT service areas included in the survey were based on the occupations listed in the OTPF-4 (AOTA, 2020a). The Provider Survey did not include a section for the HBM tenants, as the HBM is personally referenced and the providers were responding based on perceived needs for their clients (National Cancer Center, 2005).

In the third section of the Provider Survey, providers answered open-ended questions about their perspectives of the word "health," barriers clients experience to participation in OT services, factors contributing to clients' health or lack thereof, and whether or not clients would find the listed OT services helpful. Additionally, providers listed barriers and supports to referring to OT services at the IFC. The open-ended responses were intended to supplement quantitative data with more in-depth information and encourage individualized responses. The Provider Survey is located in Appendix G.

Analysis of Data

Quantitative data from this study was analyzed using descriptive statistics on Microsoft Excel (2016) program. Due to the small sample size of this study, further

statistical analysis was not possible. Qualitative data from open-ended survey responses were independently analyzed by the PI and faculty adviser to ensure all responses were included. Similar ideas and words were grouped into themes and the number of responses were included in each theme were counted. Finally, the PI and faculty adviser compared the list of themes and made adjustments as needed.

Chapter Four: Results

A total of 32 client survey responses were collected and 27 were analyzed. Four client surveys were less than 50% complete and one client did not provide consent, and therefore these five surveys were excluded from analysis. A total of 13 provider survey responses were collected and 10 were analyzed. One provider completed less than 50% of the survey and two providers did not provide consent, and therefore these three surveys were excluded from analysis.

Client Results

Chronic condition.

The majority of clients surveyed reported having a chronic condition (n=16). Of the clients who reported having a chronic condition, 41% (n=11) indicated their condition(s) impact their daily life, while 18% (n=5) reported that their condition(s) do not impact their daily life. Refer to Table 1 for a complete summary of chronic conditions and impacts on daily life.

Demographics.

The average age of client participants was 47 years (range 21-73 years of age), with the majority falling in the 31-40 year old category. The majority of clients self-identified as female (n=16, 59%) and the remaining clients self-identified as male (n=11, 41%). Refer to Table 2 for a complete summary of demographics.

Caregiver status.

Most clients reported they were not a caregiver for a family member or close friend (n=17, 63%) and most clients (n= 24, 89%) reported that they did not have a caregiver for themselves. Refer to Table 3 for a complete summary of caregiver status.

Health beliefs.

Clients responded to prompts based on tenants of the HBM, each of which is represented by a subsection below. For each subsection, data was first analyzed for the entire client sample, then based on whether or not clients reported having a chronic condition(s). Using a Likert scale, clients recorded their agreement to each statement with either Strongly Agree (coded as 4), Agree (coded as 3), Disagree (coded as 2), and Strongly Disagree (coded as 1). Refer to Table 4 for client responses to HBM prompts. Refer to Table 5 for client responses to HBM prompts comparing clients with chronic conditions and clients without.

Negative impact on daily life.

Clients first responded to the statement: "I believe that chronic conditions have a negative impact on daily life," which corresponded to the *perceived severity* tenant of the HBM. Most clients either strongly agreed (n=18, 67%) or agreed (n=6, 22%) that their chronic condition negatively impacts their daily life. The remaining clients disagreed (n=2, 7%) or strongly disagreed (n=1, 4%) with this statement. The mean response to this statement was 3.52. Clients with chronic conditions reported a slightly higher average agreement to this statement (M=3.56) than clients without (M=3.45).

Make changes to prevent.

Clients were next presented with the statement: "I can make changes to prevent, or prevent worsening of, chronic conditions," which represented the *cues to action* tenant of the HBM. Most clients strongly agreed (n=13, 50%) or agreed (n=12, 46%) with this statement and one client disagreed (n=1, 4%) with this statement. No clients selected strongly disagree and one client did not respond. The mean response to this statement

was 3.46. Clients with chronic conditions reported a lower average agreement to this statement (M=3.25) than those without (M=3.8)

Identify risk factors.

Next, the statement: "I can identify risk factors for chronic conditions" was based on the *self-efficacy* tenant of the HBM. Most clients selected agreed (n=15, 56%) or strongly agreed (n=11, 41%) with this statement, and one client disagreed (n=1, 4%) with this statement. No clients selected strongly disagreed. The mean response to this statement was 3.37. Clients with chronic conditions reported a lower average agreement to this statement (M=3.25) than clients without chronic conditions (M=3.54).

Barriers to making changes.

The following statement: "There are barriers (personal or other) to making changes to prevent, or prevent worsening of, chronic conditions" related to the *perceived barriers* tenant of the HBM. Most clients agreed (n=15, 65%) or strongly agreed (n=5, 22%) with this statement. The remaining clients either strongly disagreed (n=2, 9%) or disagreed (n=1, 4%) with this statement. Four clients did not respond. The mean response to this statement was 2.85. Clients with chronic conditions reported a higher average agreement (M=3) than those without chronic conditions (M=2.64) that there are barriers to making changes to prevent, or prevent worsening of, chronic conditions.

At risk for developing.

Finally, clients were prompted with the statement: "I believe I am at risk for developing a chronic condition or worsening of a chronic condition," which corresponded to the *perceived susceptibility* tenant of the HBM. Most clients agreed (n=12, 46%), while fewer strongly disagreed (n=7, 27%) or disagreed (n=6, 23%) with this statement.

One client strongly agreed (n=1, 4%) with this statement and one client did not respond. The mean response to this statement was 2.3. Clients with chronic conditions reported a higher average agreement (M=2.75) than clients without chronic conditions (M=1.63) to this statement.

Service areas.

The next section of the client survey stated: "Please rate your agreement to the following statements. I would benefit from OT at the IFC to address…" Below this statement was a list of OT service areas for the prevention and management of chronic conditions. Using a Likert scale, clients recorded their agreement with either Strongly Agree (coded as 4), Agree (coded as 3), Disagree (coded as 2), and Strongly Disagree (coded as 1) for each service area. Data for the service area questions were first analyzed for all clients. Then, data for clients with chronic conditions were compared to data for clients without chronic conditions.

The three highest average agreements were to the service areas "exploring new leisure interests and balancing leisure activities with other responsibilities" (M=3.52), "incorporating exercise routines into my daily life" (M=3.50), and "using community supports to manage physical and mental health needs" (M=3.48). The four lowest average agreements were to the services areas "taking care of my home (cleaning, gardening, etc.)" (M=3.12), "taking care of myself (grooming, dressing, etc.)" (M=3.12), "taking care of others (pets, children, other family members, etc.)" (M=3.07), and "managing daily medications" (M=3.04). Refer to Table 6 for client responses to OT service areas.

Chronic condition vs. No chronic condition

The highest average agreement for clients with chronic conditions was to the service area “using community supports to manage physical and mental health needs” (M=3.44), while the highest average agreement for clients without chronic conditions was to the service area “exploring new leisure interests and balancing leisure activities with other responsibilities” (M=3.73). The lowest average agreement for clients with chronic conditions was to the service area “taking care of myself (grooming, dressing, etc.)” (M=2.8). The lowest average agreement for clients without chronic conditions was to the service areas “taking care of my home (cleaning, gardening, etc.)” (M=3.18) and “taking care of others (pets, children, other family members, etc.)” (M=3.18) .

The biggest difference between average agreement for clients with chronic conditions and clients without chronic conditions was for the service area “taking care of myself (grooming, dressing, etc.)” (D=0.74). Clients without chronic conditions reported a higher average agreement to this service area (M=3.54) than clients with chronic conditions (M=2.8). Refer to Figure 1 for a comparison of clients with and without chronic conditions in terms of agreement to the OT service areas.

Themes.

Themes were extracted from responses to open-ended questions on the Client Survey. Each open-ended question is represented by a subsection below.

Impact on daily life.

Clients who reported having a chronic condition(s) explained “how this condition(s) impacts your everyday life.” Themes extracted from client responses included *stay in bed/tired, work, social participation, home management, and spirituality/religion.* Refer to Table 7 for impacts of chronic conditions on everyday life.

Health associations.

Clients then answered the question, "What comes to mind when you hear the word 'health'?" Themes from client responses included *mental health, happiness, good choices/take care of self, longevity, decreased/no pain, financial resources, family*, and *energy* were themes that emerged. Refer to Table 8 for clients' health associations.

Supports to participation.

Next, clients answered the question, "What would support your participation in the listed programs of interest?" Themes from responses to this question included *time, encouragement from a friend, more information,* and *money/insurance.* Refer to Table 9 for client-reported supports to OT participation.

Barriers to participation.

Then, clients answered the question, "What might prevent you from participating in OT services?" Themes from responses included *time, transportation, money/insurance, anxiety, childcare/family, physical/mental needs,* and *more acute needs.* One client reported that their needs are already being met. Refer to Table 10 client-reported barriers to OT participation.

Additional comments.

Impactful comments by clients included:

"Thank you for try[ing] to help. It make[s] a better world."

"OT would be wonderful. Is much needed. Is mainly missing in health maintenance."

"Thank you for the community support."

Provider Results

Demographics.

The majority of providers surveyed were female identifying Nurses/Nurse Practitioners. Other services offered at the IFC were underrepresented in the data, as evidenced by contributions from only a single Acupuncturist, Herbalist, and Shamanic Energy worker. Providers had either 0-5 years (n=4, 40%) or 6-10 years (n=4, 40%) of experience at the IFC, and one provider reported having 11+ years (n=1, 10%) of experience. One provider did not disclose years of experience. Refer to Table 11 for provider demographics.

OT referrals.

Referrals to OT were made by half of providers and half had not referred to OT. Of the providers who had referred to OT, 17% (n=4) of referrals were made for Activities of Daily Living (ADL) Skills, 17% (n=4) of referrals were made for Strength, 13% (n=3) of referrals were made for Range of Motion, 13% (n=3) of referrals were made for Coordination, 9% (n=2) of referrals were made for Neurological Issues, 9% (n=2) of referrals were made for Pain Management, 9% (n=2) of referrals were made for Cognition, 4% (n=1) of referrals were made for Return to Work, 4% (n=1) of referrals were made for Higher Level ADL Skills, and 4% (n=1) or referrals were made for Mental Health Issues. No providers reported making referrals for Sensation or for "other" reasons. Refer to Table 12 for OT referrals.

Service areas.

Providers next responded to the prompt: "Please rate your agreement to the following statements. I would refer clients to OT at the IFC to address…" A list of OT service areas for the prevention and management of chronic conditions was included

beneath this statement. Providers responded to each service area using a Likert scale and indicated their agreement with either Strongly Agree (coded as 4), Agree (coded as 3), Disagree (coded as 2), or Strongly Disagree (coded as 1).

The three highest average agreements were to the service areas "using community supports to manage physical and mental health needs" (M=3.9), followed by "incorporating exercise routines into daily life" (M=3.8) and "exploring new leisure interests and balancing leisure activities with other responsibilities" (M=3.8). The three lowest average agreements were to the service areas "managing daily medications" (M=3.4), "participating in social groups" (M=3.4), and "taking care of others (pets, children, other family members, etc.)" (M=3.4). Refer to Table 13 for provider responses to OT service areas.

Themes.

Themes were extracted from responses to open-ended questions on the provider survey. Each open-ended question is represented by the subsections below.

Helpful for clients.

Providers first responded to the prompt: "Please discuss how the listed OT services might be helpful to your clients. If you do not think they are helpful, please discuss why." In their answers, some providers also spoke more generally about the scope of OT. Several themes emerged, including *clients would find [OT] services helpful, providers didn't know OT could address [the listed service areas],* and *clients didn't know OT could address [the listed service areas].* Refer to Table 14 for provider responses to whether OT service areas would be helpful for clients.

Barriers to making OT referrals.

Providers then answered the question: “Do you experience any barriers to making referrals to OT services? If yes, please describe.” Among the responses, *availability of resource, use of the electronic system,* and *no barriers* were themes that surfaced. Refer to Table 15 for barriers to making OT referrals.

Barriers to clients participating in OT.

Next, providers answered the question: “What do you perceive as barriers for clients to follow through with their appointments in general? If you are able to comment, what are barriers for following through with OT appointments?” Themes extracted from responses to this prompt included *transportation, motivation, time management, childcare, poor health, work, compliance,* and *scared/not ready.* Refer to Table 16 for provider-reported barriers to OT participation.

Health associations.

Providers were then prompted with the following statement: “What comes to mind when you hear the word ‘health’?” Themes that emerged included *well-being, physical and mental health, taking care of self, managing life balance, performing ADLs and IADLs,* and *fullest potential.* Refer to Table 17 for providers’ health associations.

Positive impacts on client health.

Providers next responded to the question: “What do you think positively impacts the health of your clients?” Providers identified several positive impacts on the health of their clients, including themes related to *respect for clients, community, social participation, sleep, education,* and *work.* Refer to Table 18 for positive impacts on client health.

Negative impacts on client health.

Providers were then asked: "What do you think negatively impacts the health of your clients?" The most commonly identified negative impact on health, as listed by providers, was related to *lifestyle choices*, such as diet and alcohol and drug use. Other themes included *isolation/social barriers, poverty-related, lack of awareness/misinformation, discrimination, lack of access,* and *environmental impacts.* Refer to Table 19 for negative impacts on client health.

Additional comments.

A few providers offered additional comments, the most significant of which were:

"I think it would be helpful if the OT team came in and set up a few dates where they can tell the practitioners what they offer. And also, thank you for being a part of the free healthcare. It is very helpful."

"…I'm glad we have OT services at the Ithaca Free Clinic."

"Please post what you could provide to assist our patients. I did not even know I could refer to occupational therapy."

Provider vs. Client Service Areas

The service area with the highest average client agreement was "exploring new leisure interests and balancing leisure activities with other responsibilities" (M=3.52), while the service area with the highest average provider agreement was "using community supports to manage physical and mental health needs" service area (M=3.9). The service area with the lowest average provider agreement was "understanding of the healthcare system, scheduling appointments, and advocating for health needs" (M=3.2), and the service area with the lowest average client agreement was "managing daily medications" (M=3.04).

The service area with the biggest difference in average agreement between client and provider responses was “taking care of myself (grooming, dressing, etc.)” (D=0.58). The average response to this service area was higher for providers (M=3.7) than for clients (M=3.12). The average provider agreements were higher than the average client agreements for every service area except for “understanding of the healthcare system, scheduling appointments, and advocating for health needs.” For this service area, the average client response was 3.37 and the average provider responses was 3.2. Refer to Figure 2 for a comparison of client and provider average agreements to OT service areas.

Chapter Five: Discussion

The Need for OT Services

The first aim of this study was to determine the need for OT services to address the prevention and management of chronic conditions for clients at the IFC. Previous literature has explored the role of OT with this population in primary care settings and has suggested specific interventions for individuals with, or at risk for, chronic conditions (Leland et al., 2017; Dahl-Popolizio et al., 2016; Muir, 2012; Altschuler et al., 2012). Furthermore, prior research has deemed OT intervention for the prevention and management of chronic conditions to be effective (Jackson et al., 1998; Pyatak et al., 2019; Uyeshiro Simon & Collins, 2017). This study expanded on these findings by examining the needs of a specific population—uninsured or underinsured clients in Tompkins County, New York receiving services at the IFC.

Impacts of chronic conditions.

One client in particular detailed the many impacts of having multiple chronic conditions:

> *[My] #1 problem, IBS, makes me spend unpredictable hours/times in [the] bathroom, interfering with [my] ability to hold down a job, have a social life, attend a faith community, and even get to healthcare appointments.*

This comment—among impacts listed by other clients including *staying in bed and fatigue*, *work participation, social participation, home management, and spirituality/religion*—detailed the physical, social and emotional tolls of chronic conditions on everyday life. These results were in accordance with previous research. The

impacts of chronic conditions on everyday valued occupations and overall physical and mental health were well-documented, especially when an individual has multiple chronic conditions (Cleveland Clinic, 2020; U.S. Department of Health and Human Services, 2016; AOTA, 2015; Buttorf et al., 2014; Cameron, 2019). Furthermore, clients expressed a lack of participation in meaningful occupations as a result of their chronic conditions.

According to Hocking (2017), when external aspects impact participation in meaningful occupations that promote well-being, individuals experience occupational deprivation. Occupational deprivation is one type of occupational injustice, which occurs when social conditions give rise to inequities in accessing or participating in healthful occupations across different groups of people, where some people benefit and others experience occupations that are harmful to health and well-being (Hocking, 2017). The client's quote above is an example of occupational injustice experienced by an individual with MCCs. The client depicts difficulty attending healthcare appointments, a health promoting occupation that would help to manage their conditions, as a result of their chronic conditions.

Results from this study described the impacts of chronic conditions on everyday life and support the role of OT in chronic disease intervention at the IFC. AOTA (2015) outlines several roles for OT in chronic disease prevention and management, such as improving functional status in ADLs and IADLs, educating individuals on energy conservation techniques to manage associated fatigue, providing task adaptations to increase independence, incorporating health management tasks into daily routines, and facilitating coping strategies for psychosocial well-being.

Not only are OT practitioners well-positioned to meet the needs of this population, they have an obligation to do so. According to the Philosophical Base of Occupational Therapy, participation in valued occupations is essential to health prevention, promotion and restoration and "all individuals have an innate need and right to engage in meaningful occupations throughout their lives" (AOTA, 2017, para. 1). Clients with chronic conditions who participated in this study could benefit from OT services because they identified decreased participation in valued and health-promoting occupations, and therefore experienced occupational injustice.

Client responses to service areas.

In order to determine which specific OT services clients would benefit from, analysis of their responses to the listed services areas was needed. Overall, clients with chronic condition(s) reported a lower average agreement to all of the listed service areas, as compared to clients without a chronic condition(s). This finding may be attributed to several reasons, such as clients with chronic conditions attending to more urgent medical needs, decreased health literacy, and already having their needs met.

More urgent medical needs.

It is possible that clients with chronic conditions deemed OT services less necessary than other more urgent medical care. In the open-ended response section, one participant identified "attending to more urgent medical needs" as a barrier to participating in OT services. Maslow's Hierarchy of Needs asserts that physiological needs, such as breathing, food, water, shelter, clothing, and sleep must be fulfilled prior to accessing safety and security, love and belonging, self-esteem, and self-actualization (Research History, 2012). Urgent medical needs are considered basic physiological needs

and must be fulfilled prior to the other hierarchies. Clients identified that their basic physiological and/or safety and security needs have not been met, and therefore they view OT services as not immediately necessary.

Health literacy.

It was noted by the PI that at least two participants incurred language and possible literacy barriers when responding to survey questions. Although one client was able to translate the survey with a mobile app, it is possible that this translation led to a different interpretation of OT services than was intended. The client survey was written with efforts to exclude profession-specific jargon, however, perhaps the survey did not accurately reflect the literacy levels of clients who participated in the survey. In order to remain unbiased, the researcher was unable to offer clients any clarifying information in order to uphold the integrity of the research design. These results brought attention to the health literacy needs of clients served by the IFC.

The WHO (2020b) suggests health literacy is a skillset beyond just the ability to read health materials and make appointments, but rather encompasses the confidence required to make changes to personal lifestyles and improve overall personal health. Furthermore, health literacy is a SDOH that impacts an individual's ability to access medical care (Healthy People, 2020a). However, if individuals are unable to make healthcare appointments in the first place, then they may not even be able to access a diagnosis of a chronic condition. Perhaps some of the clients who reported that they do not have a chronic condition actually have an undiagnosed chronic condition or were limited in their ability to interpret a physician's diagnosis, and therefore identified with the OT service areas. Without access to medical records, the survey relied solely on the

reporting of clients, so there was no way to determine the accuracy of their reports in terms of whether or not they had one or more diagnosed chronic conditions.

While health literacy possibly impacted the results of this study, this finding highlights the importance of health literacy as a part of OT intervention with this population. OT practitioners have the opportunity to intervene by matching client literacy abilities, cultural needs, and verbal, cognitive, and social skills (AOTA, 2017). Additionally, language barriers between the client and provider have been shown to contribute to poor provider-client communication (Agency for Healthcare Research and Quality, 2018). In order to uphold client-centered care, good communication between the client and provider must be applied to lead to improved health outcomes (Weiner et al., 2013). Therefore, addressing health literacy by providing adaptations to health materials that are appropriate for literacy levels and language needs is an identified need for this population.

Medication management.

When comparing responses of clients with and without chronic conditions, clients with chronic conditions reported a lower than average agreement to the medication management service area than clients without chronic conditions. This result was inconsistent with previous literature, as AOTA specifically identifies medication management as a role for OT practitioners in interventions with clients who have chronic conditions (2015). Not only is medication management an established area for OT intervention, OT services can potentially lead to improved medication management and have been proven to be effective in increasing medication adherence for clients with chronic health conditions (Schwartz & Smith, 2017; Schwartz et al., 2017). It was unclear

why clients with chronic conditions did not identify the medication management service area as a need. Perhaps clients are already managing their medications appropriately or have help to manage medications.

Client vs. Provider responses to service areas.

Comparing client and provider responses helped determine if providers have an accurate understanding of what was preventing clients' participation and how this could be addressed by OT. Moreover, these results provided insight on any current gaps in care for clients. It is important to acknowledge that 70% of provider participants were female identifying Nurses or Nurse Practitioners, so the sample of provider responses was largely represented by this profession and may have skewed the responses.

Providers reported a significantly higher average agreement to the "taking care of myself" OT service area than clients. It is possible that this result is due to the population that was surveyed. While providers were asked to rate their agreement in terms of referring all clients of the IFC to OT services, including those who come in for regular appointments, only clients who attended the clinic walk-in hours were recruited to participate in the study. Because the clients surveyed were attending the clinic for short-term, acute needs, it is possible they were operating at a higher level of function than other clients who have consistent appointments with providers for more complex or chronic needs. Therefore, perhaps these participants were less likely to benefit from services addressing basic living needs, such as grooming, hygiene, and toileting. It is possible that the providers were thinking about a different subset of clients when responding to this question.

Providers reported a higher average agreement than clients to all but one of the listed OT service areas. Clients reported a higher average agreement to the "understanding of healthcare" OT service area than providers. This finding suggests there are more health literacy concerns among clients than providers are privy to and points to a need for attention to health literacy concerns for the community served by the IFC. Furthermore, these results could provide an opportunity to educate providers on the importance of accommodating for their clients' health literacy needs and how to implement these changes.

Supports and Barriers to OT Participation

A second aim of this study was to identify factors that support or impede client participation in OT services from both client and provider perspectives. The Health Belief and PEO Models guided this portion of the study. They were used to interpret survey results and helped to consider the impact of personal health beliefs and environmental influences, respectively.

Health Belief Model.

The HBM was employed to better understand why there was decreased engagement in OT programming at the IFC, as this public health model helped discern why people make certain decisions about their health (National Cancer Institute, 2005).

Perceived susceptibility.

To gauge perceived susceptibility, clients rated their agreement to the statement: "I believe I am at risk for developing a chronic condition or worsening of a chronic condition." Clients without chronic conditions demonstrated a lower perceived susceptibility of developing a chronic condition, as compared to clients with chronic

conditions, who demonstrated a higher perceived susceptibility of developing an additional chronic condition. Because clients with chronic conditions had a higher perceived susceptibility, according to the HBM, they were more likely to seek out care to prevent worsening of their condition or developing an additional chronic condition (National Cancer Institute, 2005). Therefore, results of the perceived susceptibility tenant alone do not explain underutilization of OT services by clients with chronic conditions.

Perceived severity.

In order to determine perceived severity, clients rated their agreement to the statement: "I believe that chronic conditions have a negative impact on daily life." Clients with chronic conditions indicated higher perceived severity of chronic conditions than those without chronic conditions. The results of this tenant suggest clients with chronic conditions could be more likely to seek care than those without because they perceive more severe impacts of their condition(s).

Perceived barriers.

For the perceived barriers tenant, clients rated their agreement to the statement: "There are barriers (personal or other) to making changes to prevent, or prevent worsening of, chronic conditions." Clients with chronic conditions perceived more barriers to treatment than clients without chronic conditions. Although clients with chronic conditions indicated higher perceived severity, which typically suggests a high likelihood of making health behavior changes, these clients also perceived greater barriers to treatment. Therefore, the likelihood of making changes for those with chronic conditions is decreased according to the HBM. This could explain decreased attendance at OT appointments—although clients with chronic conditions believe they are at risk and

also believe chronic conditions to be severe, they experience barriers that make it difficult to commit to or attend appointments.

Self-efficacy.

To determine self-efficacy, clients rated their agreement to the statement: "I can identify risk factors for chronic conditions." The results of this study demonstrated that clients with chronic conditions, as compared to those without, demonstrated lower self-efficacy. Self-efficacy is defined as the self-perceived inability to make changes to prevent or prevent worsening of chronic conditions (National Cancer Institute, 2005). OT intervention focused on improving self-efficacy for clients with MCCs has been demonstrated to improve activity participation and quality of life (Garvey et al., 2015). Since clients with chronic conditions demonstrated decreased self-efficacy, they would benefit from OT intervention to address self-efficacy and improve health outcomes.

Additionally, one provider noted that motivation might prevent participation and another provider listed "compliance" as a barrier to participation. Motivation and compliance might be reflected in the self-efficacy construct of HBM, as individuals who feel less confident in their ability to make changes may be less motivated to do so (National Cancer Institute, 2005). Perhaps providers are identifying lower levels of self-efficacy for clients with chronic conditions as a barrier to treatment, which is consistent with self-reported low self-efficacy for clients with chronic conditions.

Perceived benefits.

Clients with chronic conditions acknowledged fewer potential benefits to treatment for their condition(s) than those without chronic conditions. This result could point to an opportunity for intervention with clients who do not have chronic conditions.

Since those without chronic conditions in this study perceived greater benefits to treatment, high self-efficacy, and little barriers, and are therefore more likely to take action for their health, they could benefit from preventive programming. Lifestyle Redesign is an intervention approach that addresses the prevention and management of chronic conditions through the development of healthy routines (Uyeshiro Simon & Collins, 2017). Lifestyle Redesign intervention was first used with the well elderly population, meaning the recipients of Lifestyle Redesign did not have an existing condition, but were likely to develop one. This intervention has been demonstrated to help clients significantly improve quality of life, self-efficacy, and functional abilities (Uyeshiro Simon & Collins, 2017).

While the primary focus of programming at the IFC is for clients who are already a part of the Chronic Care Program, those who are considered part of the "well" or "at-risk" population are also an important target population for OT services. According to AOTA (2015), OTs have a role in the prevention of dysfunction, facilitation of a healthy lifestyle, and helping clients incorporate healthy habits and routines into their existing lifestyles. Therefore, OTs have a unique opportunity to help clients at the IFC prevent the development of chronic conditions in addition to providing interventions for clients in the Chronic Care Program who have existing chronic conditions.

Person-Environment-Occupation Model.

The PEO Model was also referenced in this study, as it asserted that there exists an interactive relationship between the environment, the person, and the occupations the individual engages in. Specifically, this model was used to understand personal and

environmental variables that could account for decreased participation in OT services at the IFC (Law et al., 1986).

Person

According to the PEO model, the person must be considered fully in addressing mind, body and spirit (Law et al., 1986). Mental health was mentioned by both clients and providers in their respective survey responses. For example, in terms of barriers to participating in OT services at the IFC, two clients mentioned anxiety. Previous literature has documented the cyclical nature of chronic physical conditions and chronic mental conditions and the frequent co-occurrence of the two (NIMH, n.d.). For clients at the IFC, not attending health appointments due to anxiety could exacerbate physical symptoms of their condition. While it is clear from their survey responses that providers acknowledge the importance of mental health, only one provider reported making a referral to OT for mental health needs. OT practitioners have a distinct role in addressing mental health, physical health, and overall well-being for individuals with chronic conditions and those who are at risk for developing chronic conditions. Therefore, it is important to educate other IFC providers on the scope of OT for mental health, especially for individuals with chronic conditions. In turn, this may increase referrals to OT at the IFC, enabling OT practitioners to better address the mental health needs of IFC clients.

Environment

Cultural, socio-economic, institutional, physical and social environments can serve as either supports or barriers to occupational performance (Law et al., 1986). Providers acknowledged both the social and environmental challenges their clients experience in terms of barriers to participation. For example, both clients and providers

listed transportation, time, poor health, and lack of childcare as barriers to participation in OT services. These barriers could be due to a lack of financial resources to take time off of work, pay for childcare, and/or obtain adequate transportation. Alternatively, perhaps clients do not live close to a bus stop or other public transportation in order to travel to OT appointments.

In terms of the social environment, both client and provider responses point to the importance of social support in following through with health behaviors. Four clients reported that encouragement from a friend would support their participation and, similarly, two providers listed social participation as a positive impact on the health of their clients. For individuals with chronic conditions, the support of family and friends is often needed for assistance with physical care, preparing meals and competing housework, transportation, medication management, and emotional support (Ploeg et al., 2017).

Providers identified several SDOH in their survey responses, including lack of access to healthcare, food, insurance, employment, family supports, and consistent income. Social and economic barriers and poor lifestyle habits also negatively impact the health of their clients. These results are consistent with previous literature which has stated that social, political, and economic inequalities result in health disparities (CDC, 2018). For example, low SES has been linked to poor health in a study investigating the development of various types of cancers (Xiao et al., 2017). In turn, personal factors and the social and physical environment can positively or negatively impact occupational performance. It is clear that clients' social and physical environmental circumstances impact both their overall health and ability to participate in OT services.

Occupation

Clients listed several impacts of chronic conditions on their everyday lives. Their responses indicated they experienced occupational injustice in the form of occupational deprivation, as they were unable to participate in valued and health-promoting occupations (Hocking, 2017). Furthermore, a few providers mentioned in their survey responses that their clients experience discrimination in their daily lives. Providers specifically used the terms "racism" and "hatred" to describe negative impacts on their clients' health. Occupational injustice due to the health consequences of chronic conditions are amplified by health disparities, especially racial disparities (Agency for Healthcare Research and Quality, 2018; Sohn, 2017; Shi et al., 2014). According to Hocking (2017), this population was therefore subjected to occupational marginalization and, more broadly, occupational apartheid.

The person, environment, and occupation cannot truly be separated as they comprise a dynamic, ever-changing system (Law et al., 1986). The combination of clients' personal factors, such as physical and mental symptoms of chronic conditions, social conditions, such as racial injustice, and the physical environment, such limited access to transportation, impede occupational participation. For the purpose of this study, it is suggested that a combination of personal health belief and environmental barriers leads to decreased participation in OT services at the IFC. In order to address this phenomenon specifically for clients at the IFC, clients must be effectively supported in accessing OT services.

Supports and Barriers to Making OT Referrals

The third and final aim of this study was to examine the supports and barriers experienced by providers when making referrals to OT, specifically at the IFC. The majority of providers listed no barriers to making referrals to OT services, however it is important to note that half of providers had never referred their clients to OT. Potential reasons for providers not referring to OT include lack of awareness of OT services, limited knowledge of the role of OT in general, and limited understanding of the possible benefits OT could offer clients with chronic conditions. Furthermore, one provider listed limited availability of OT services as a barrier to making referrals. As OT students only provide services for three hours one day a week and there is only one OT faculty member at the IFC, providers may be prioritizing which clients they refer to OT services based on availability of services.

Improvement of referrals to OT.

There are several ways to address barriers to making referrals to OT services at the IFC. Since half of the providers who responded to the survey had not referred their clients to OT in the past, perhaps more awareness of OT services would lead to a greater number of referrals for clients who are in need. If possible, greater representation of OT at the IFC could serve as a reminder for providers to refer to services. Since the Ithaca College Department of Occupational Therapy resources may be limited, clients served by the IFC could benefit from additional networking in the community to bring on more OT practitioners as volunteers. Most importantly, educating other providers at the IFC regarding the scope of OT could lead to a better understanding of the services offered by OT, and therefore, increased referrals for client needs.

Implications for OT Practice.

This study investigated the need for OT services to address and prevent chronic conditions, supports and barriers to client participation in OT services, and supports and barriers to providers making referrals to OT at the IFC. Throughout each of these areas investigated in the study, client-centered care was a common thread. Client-centered care is important at the IFC and all other practice settings where OT is being offered.

One way in which OT practitioners can uphold client-centered care at the IFC and in other settings is by evaluating and treating the client in terms of both mental and physical health needs. OT practitioners can help clients to manage their mental health symptoms by facilitating client advocacy for changes of medications that may be causing mental health symptoms. If mental health needs cannot be met by OT practitioners alone, they can support clients by referring to a mental health professional in the community and/or directing the client to community resources, such as support groups.

OT practitioners can also prioritize client-centered care by considering systemic impacts associated with SDOH. For example, OT providers might consider discharge recommendations, such as durable medical equipment and community resources, that are both financially and geographically accessible to the client. Furthermore, OT practitioners must consider social aspects that contribute to health disparities, such as racial injustice. The results of this study also highlight the importance of acknowledging literacy levels in client education and intervention. Facilitating materials and communications that meet the health literacy needs of the population served will increase client adherence and, therefore, improve service outcomes.

Similarly, it is hoped that educating clients regarding the outcomes and potential benefits of OT services will lead to increased participation in services and facilitate an open conversation with clients, therefore increasing their involvement in treatment. In order to help achieve this at the IFC, the PI, in collaboration with the academic advisor and Director of Chronic Care, created an educational handout for clients of the Chronic Care Program. This insert, to be used in tandem with a brochure outlining the general role of OT, lists OT services that specifically address the needs of clients with chronic conditions. A definition of chronic conditions, OT's role with chronic conditions, the service areas listed in the survey, and outcomes of OT services are included in the handout (Appendix H).

In addition to educating clients on the benefits of OT services, educating other health professionals on the role of OT in the prevention and management of chronic conditions serves to advocate for OT's role on the primary healthcare team. Throughout the recruitment process, several clients expressed curiosity regarding the listed OT intervention areas and their relation to the OT profession. Similarly, several providers reported on the survey they did not know OT could address the listed services areas. One provider even requested further education on the scope of OT. Educating other health professionals is of particular importance at the IFC, given the large array of providers from different backgrounds and the opportunity for interdisciplinary collaboration.

Finally, OT practitioners can contribute to the mitigation of barriers experienced by clients with chronic conditions or those who are at risk for chronic conditions through interdisciplinary problem-solving approaches. There are many different disciplines represented at the IFC, and therefore many providers with varying perspectives. By

utilizing creative problem-solving approaches, OT practitioners have the unique opportunity to bridge the gap in current primary care services and meet the complex needs of clients with chronic conditions and those who are at risk for developing chronic conditions. For instance, OT practitioners can consult with the referring clinician and provide details regarding client context and daily routines that might be otherwise overlooked (Waite, 2014). This is just one example of the role of OT practitioners with this population and may not be feasible at the IFC given the one-time-per-week frequency of OT services offered. Other examples include adapting the client's social and physical environment to increase access to care and implementing secondary preventive approaches to lessen the impact of chronic conditions.

In summary, the factors that contribute to chronic conditions and the impacts of physical and mental health symptoms are complex. Some of the self-identified needs of clients at the IFC in terms of the prevention and management of chronic conditions include attention to SDOH and also consideration of occupational injustice and health literacy concerns. As clients without chronic conditions are more likely to take action for their health, as evidenced by their responses to the HBM prompts, they could potentially benefit from preventive programming, such as education regarding risk factors for developing chronic conditions and incorporating lifestyle changes into daily routine. Not only did certain health beliefs serve as barriers for clients in terms of participating in OT services, social determinants of health impeded clients' ability to attend appointments. In order to better facilitate OT referrals at the IFC, both clients and healthcare providers must be educated on the benefits and scope of OT services for the prevention and management of chronic conditions.

Chapter Six: Summary, Conclusion, and Recommendations

Summary

This research study investigated OT services at the Ithaca Free Clinic—a free, community-based primary health care clinic in Ithaca, NY. The results of this study highlighted areas that can be improved upon to increase access to OT services at the IFC for clients with and without chronic conditions. Results included both client and provider perspectives.

The majority of clients had chronic conditions and indicated their conditions impacted their everyday lives. Clients indicated the most interest in leisure pursuits and the least interest in managing their medications. Using community supports for health needs was identified by clients with chronic conditions as the most beneficial service area and basic living skills, such as grooming and dressing, as the least beneficial. Overall, the needs of clients with chronic conditions and the needs of clients without chronic conditions varied but could both be addressed by OT practitioners.

Most providers were female-identifying Nurse/Nurse Practitioners and half of providers had referred to OT. Providers reported their clients would benefit the most from using community supports for health needs. Clients would gain the least benefit from managing daily medications, participating in social groups, and help caring for others, such as family members or pets, according to providers. Providers were largely represented by one profession who, in addition to clients with chronic conditions, identified using community supports for health needs as an area of importance for OT intervention.

The results of this study indicated that occupational injustice is experienced by clients at the IFC due to the many impacts of chronic conditions on everyday life. Furthermore, providers mentioned that their clients' health is negatively impacted by instances of discrimination and racism. Therefore, OT intervention is needed, both at the individual and systemic levels, to address occupational injustice and increase participation in valued occupations. The survey results also identified attending to more urgent medical needs and health literacy concerns as specific needs of clients at the IFC in terms of OT service areas. OT practitioners can use a client-centered approach by considering SDOH present in the client's environment and varying reading levels and language needs associated with health literacy concerns.

In terms of barriers to client participation in OT services at the IFC, both personal health beliefs, reflected in the HBM, and interactions of the person, environment, and occupation, reflected in the PEO Model, were contributing factors (National Cancer Institute, 2005; Law et al., 1986). According to survey results based on the HBM, individuals with chronic conditions could benefit from education on the scope and outcomes of OT for the prevention and management of chronic conditions in order to increase their participation in OT services. Clients without chronic conditions identified perceived benefits to OT treatment, high self-efficacy, and few perceived barriers. According to the HBM, they were likely to take action for their health, and therefore could benefit from preventive programming to reduce the risk of developing chronic conditions.

The PEO model was also reflected in the results of this study, as there were both personal and environmental factors that influenced occupational participation and,

ultimately, perpetuated occupational injustice. Providers and clients mentioned mental health in their survey responses—both as components of good health and barriers to participation in OT services. Mental illnesses are chronic conditions themselves and should therefore be addressed by OT practitioners (U.S. Department of Health and Human Services, 2010). In regard to environmental impacts, SDOH were listed by clients and providers alike in terms of barriers to participation and negative impacts on health.

Whether due to client factors such as physical and mental health, personal beliefs, the social environment, and/or the physical environment, a combination of many different aspects can bring about or aggravate existing chronic conditions. When providing care for this population, OT practitioners must consider these dynamic and interacting challenges clients face. OT practitioners can address the unique needs of clients by acknowledging and, when possible, adapting social and structural barriers in addition to health beliefs that are detrimental to clients' overall health and participation in OT services.

In order to address the self-identified needs of this population, clients must be more supported in accessing OT services at the IFC. While some providers at the IFC had referred to OT in the past, the other providers might not have been aware of the scope of OT, especially in terms of intervention for individuals with chronic conditions. This could therefore limit their likelihood of referring to OT. Increased referrals to OT services may be achieved by educating providers at the IFC on OT intervention for the prevention and management of chronic conditions.

Conclusion

1. Factors contributing to the development and worsening of chronic conditions are complex and often have both physical and mental implications.
2. As a result of physical and mental symptoms of chronic conditions and SDOH, clients at the IFC reported decreased participation in meaningful and health-promoting occupations, and therefore experienced occupational injustice.
3. There is a need for OT intervention for clients with chronic conditions and clients a part of the "well" or "at-risk" populations.
4. OT practitioners can address the needs of this population by acknowledging and adapting individual, structural, and social barriers in addition to health beliefs that may hinder participation in OT services.
5. Advocacy for the profession, including educating clients and other health professionals on the scope of OT, is key to OT involvement in the primary care team.

Future Directions: IFC and Beyond.

Results of the current study provided several directions for future research, both at the IFC and within other community-based settings. First, a focus group with current clients at the IFC could provide richer qualitative data in terms of client needs and environmental barriers specific to the local community. Similarly, a focus group with current providers at the IFC could provide more insight on their understanding of the scope of OT and the referral process specific to the IFC. While this study identified self-reported OT service areas clients would find most beneficial and OT service areas

providers would most likely refer to, future research is needed to implement these services at the IFC. Future research is also needed to further develop OT programming for those who are at risk for chronic conditions.

Identifying supports and barriers OT practitioners experience to providing services at the IFC could serve to enhance access to OT services at the IFC. For example, the current role of OT at the IFC from the OT provider perspective could offer a baseline of current services and highlight possible opportunities for collaboration with other disciplines. This information could inform the IFC's plan for communication between providers, interdisciplinary education, team building, and potentially more cohesive services for clients with and without chronic conditions. It would also be worthwhile to explore supports and barriers in terms of the unique delivery of services at the IFC, particularly their partnership with higher education institutes, such as the Ithaca College Department of Occupational Therapy. Although this partnership can pose logistical challenges, there may also be a distinct value in students providing care for clients.

As the results of this study highlighted the need for preventive services for "well" and "at-risk" populations, future studies could explore the efficacy of this programming at the IFC. Numerous studies have been conducted regarding the efficacy of Lifestyle Redesign OT intervention, originally used with the well population (Jackson et al., 1998; Uyeshiro Simon & Collins, 2017; Pyatak et al., 2019). Future studies can build on these results by developing a pilot program for OT intervention to prevent the development of chronic conditions. This program could trial educational programs for well and at-risk populations, including identifying risks for developing chronic conditions and building healthy habits into existing routines.

More broadly, additional research is needed to supplement existing literature regarding the efficacy of OT intervention for the prevention and management of chronic conditions. While some literature exists regarding potential roles for OT practitioners as part of a primary care team, there is very little research examining the efficacy of OT interventions for individuals with chronic conditions, or at risk for chronic conditions, in primary care settings (Leland et al., 2017; Dahl-Popolizio et al., 2016; Altschuler et al., 2012; Muir, 2012). Additional research is needed on the role of OT with this population in order to ensure that the needs of people with chronic conditions are fully met and to further establish the distinct value of the OT profession in this emerging practice area.

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Table 1

Client: Chronic Condition and Everyday Impacts

Variable	%	n
Chronic condition		
Yes	59	16
No	41	11
Everyday impacts		
Yes	41	11
No	18	5

Table 2

Client: Demographics

Variable	%	n
Age		
20-30	7%	2
31-40	26%	7
41-50	19%	5
51-60	22%	6
61-70	15%	4
71-80	11%	3
Gender		
Male	41%	11
Female	59%	16

Table 3

Client: Caregiver Status

Variable	%	n
In the role of caregiver		
Yes	37%	10
No	63%	17
Has a caregiver		
Yes	7%	2
No	89%	24
Did not disclose	4%	1

Table 4

Client: Agreement to Health Belief Model Prompts

	Agreement				
Belief	Strongly Agree (n)	Agree (n)	Disagree (n)	Strongly Disagree (n)	Mean Response
Negative impact on daily life	18	6	2	1	3.52
Make changes to prevent	13	12	1	0	3.46
Identify risk factors	11	15	1	0	3.37
Barriers to making changes	5	15	1	2	2.85
At risk for developing	1	12	6	7	2.30

Table 5

Client: Agreement to Health Belief Model Prompts: Chronic vs. No Chronic Condition

	Chronic Condition	No Chronic Condition
Belief	Mean Response	Mean Response
Negative impact on daily life	3.56	3.45
Make changes to prevent	3.25	3.80
Identify risk factors	3.25	3.54
Barriers to making changes	3.00	2.64
At risk for developing	2.75	1.63

Table 6

Client: Agreement to Service Areas

Service area	Mean	Standard Deviation
Leisure	3.52	0.64
Exercise routines	3.50	0.51
Community supports	3.48	0.64
Education	3.38	0.64
Understanding of healthcare	3.37	0.74
Sleep	3.37	0.69
Healthy food	3.31	0.88
Societal groups	3.19	0.68
Transportation	3.19	0.98
Work or volunteer	3.15	0.73
Taking care of home	3.12	0.71
Taking care of myself	3.12	1.11
Taking care of others	3.07	0.73
Medication management	3.04	0.87

Table 7

Client: Daily Impact

Impact on daily life	Responses (n)
Stay in bed/tired	4
Work	3
Social participation	2
Home management	1
Spirituality/religion	1

Table 8

Client: Health Associations

Health associations	Responses (n)
Mental health	4
Happiness	3
Good choices/take care of self	3
Longevity	2
Decreased/no pain	2
Financial resources	2
Family	1
Energy	1

Table 9

Client: Supports to OT Participation

Supports	Responses (n)
Time	5
Encouragement from a friend	4
More information	3
Money/insurance	3

Table 10

Client: Barriers to OT Participation

Barriers	Responses (n)
Time	10
Transportation	7
Money/insurance	3
Anxiety	2
Child care/family	2
Physical/mental needs	2
More acute needs	1
Needs being met already	1

Table 11

Provider: Demographics

Variable	%	n
Provider type		
Nurse/Nurse Practitioner	70%	7
Acupuncture	10%	1
Herbalist	10%	1
Shamanic Energy Worker	10%	1
Chiropractor	0%	0
Physician	0%	0
Massage therapist	0%	0
Women's health	0%	0
Nutrition	0%	0
Years at the IFC		
0 – 5	40%	4
6 – 10	40%	4
11+	10%	1
Did not disclose	10%	1

Table 12

Provider: OT Referrals

Variable	%	n
Referred to OT		
Yes	50%	5
No	50%	5
OT Referral		
ADL skills	17%	4
Strength	17%	4
Range of motion	13%	3
Coordination	13%	3
Neurological issues	9%	2
Pain management	9%	2
Cognition	9%	2
Return to work	4%	1
Higher level ADL skills	4%	1
Mental health issues	4%	1
Sensation	0%	0
Other	0%	0

Table 13

Provider: Agreement to Service Areas

Service area	Mean	Standard Deviation
Community supports	3.9	0.32
Exercise routines	3.8	0.42
Leisure	3.8	0.42
Work or volunteer	3.7	0.48
Taking care of self	3.7	0.48
Transportation	3.7	0.48
Sleep	3.6	0.70
Take care of the home	3.6	0.52
Education	3.6	0.70
Managing daily medications	3.5	0.53
Social groups	3.4	0.70
Taking care of others	3.4	0.70
Healthy food	3.3	0.67
Understanding of healthcare	3.2	0.79

Table 14

Provider: Helpful for Clients

If OT services are helpful	Responses (n)
Services helpful for clients	4
Providers didn't know OT could address	3
Clients didn't know OT could address	1

Table 15

Provider: Barriers to Making OT Referrals

Barriers	Responses (n)
None	5
Availability of services	1
Use of the system	1

Table 16

Provider: Barriers to Clients Participating in OT

Barriers	Responses (n)
Transportation	5
Scared, not ready	1
Motivation	1
Time management	1
Childcare	1
Poor health	1
Work	1
Compliance	1

Table 17

Provider: Health Associations

Health Associations	Responses (n)
Well-being	3
Physical and mental health	2
Taking care of self	2
Managing life	1
Balance	1
Performing ADLs and IADLs	1
Fullest potential	1

Table 18

Provider: Positive Impacts on Client Health

Positive Health Impacts	Responses (n)
Respect for clients	2
Community	2
Social participation	2
Sleep	1
Education	1
Work	1

Table 19

Provider: Negative Impacts on Client Health

Negative Health Impacts	Number of responses (n)
Lifestyle choices	7
Isolation/social barriers	5
Poverty related	5
Lack of awareness/misinformation	2
Discrimination	2
Lack of access	2
Environmental impacts	1

Figure 1

Client: Agreement to Service Areas: Chronic vs. Non-Chronic Condition

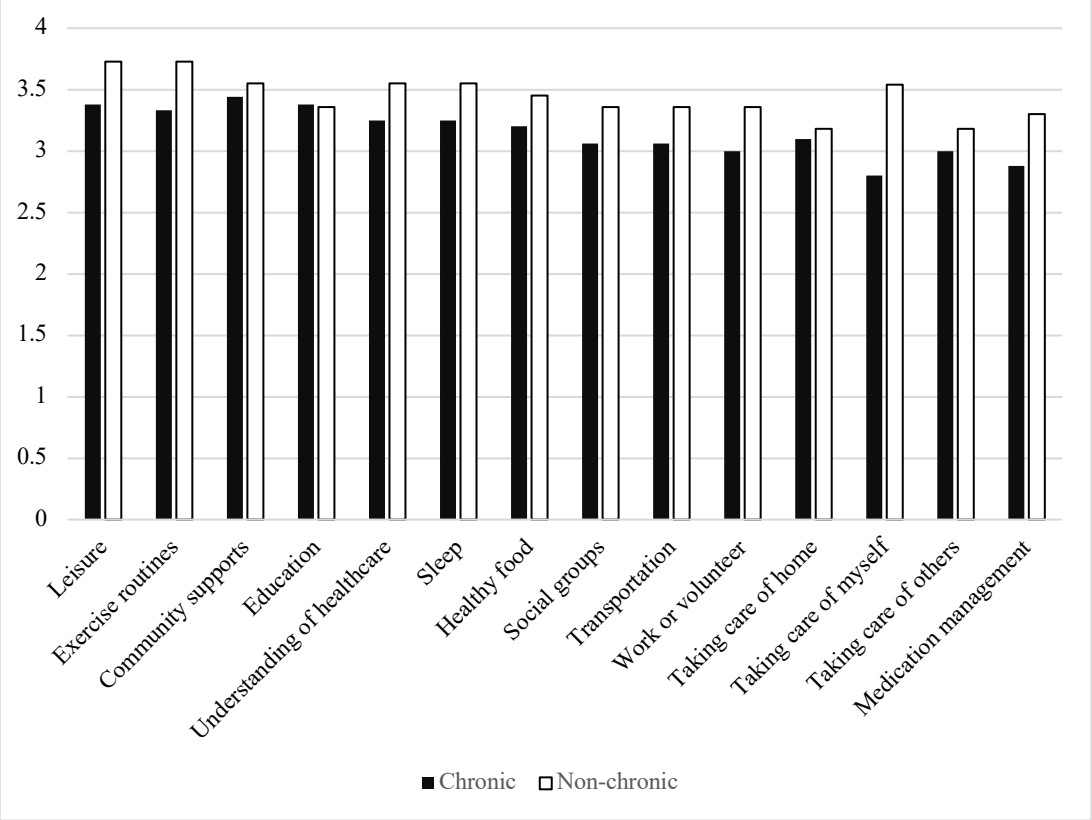
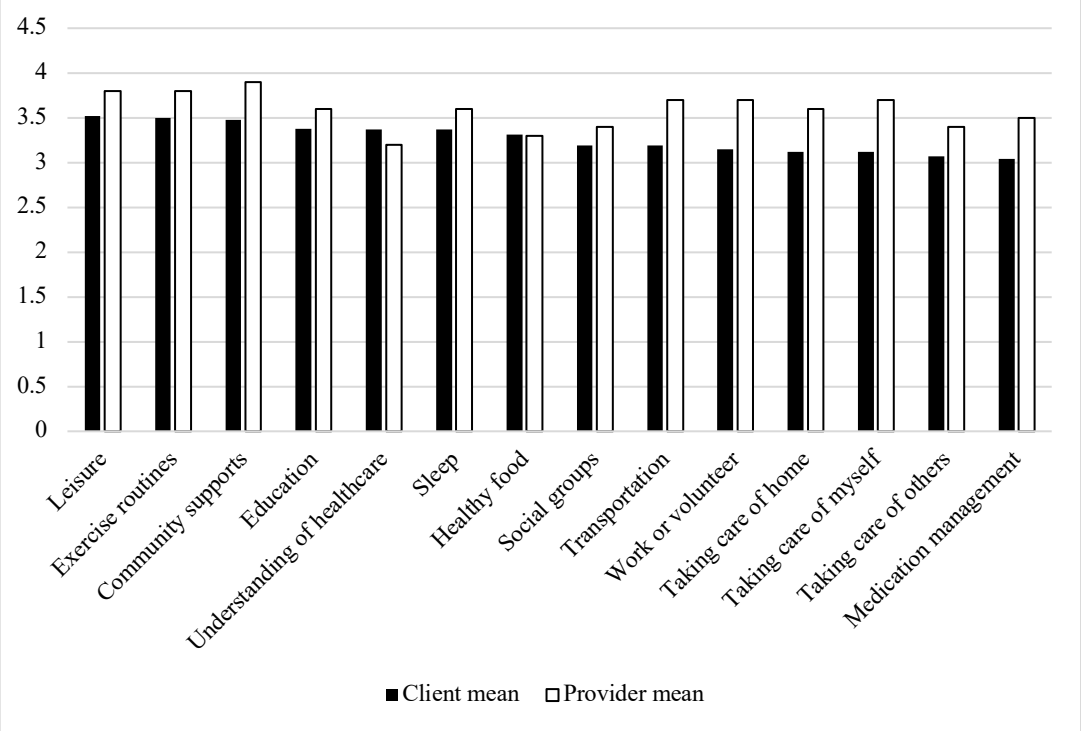


Figure 2

Client vs. Provider Agreement to Service Areas



Appendix A: IRB Approval Letter

Ithaca College IRB *Approval Notification*

To: Ruth Cohen
From: Warren Calderone
Subject: Protocol #115
Date: 11/26/2019

Re: [IRBID]The Role of Community-Based Occupational Therapy in the Prevention and Management of Chronic Conditions for Clients of the Ithaca Free Clinic

Thank you for submitting your proposal to the Institutional Review Board for Human Subjects Research (IRB). You are authorized to begin your project. This approval is issued under the Ithaca College's OHRP Federal-wide Assurance #00004870 and will remain in effect for a period of one year from the date of authorization.

Please add the IRB approval number (IRB [IRBID]) to ALL recruitment and consent materials.

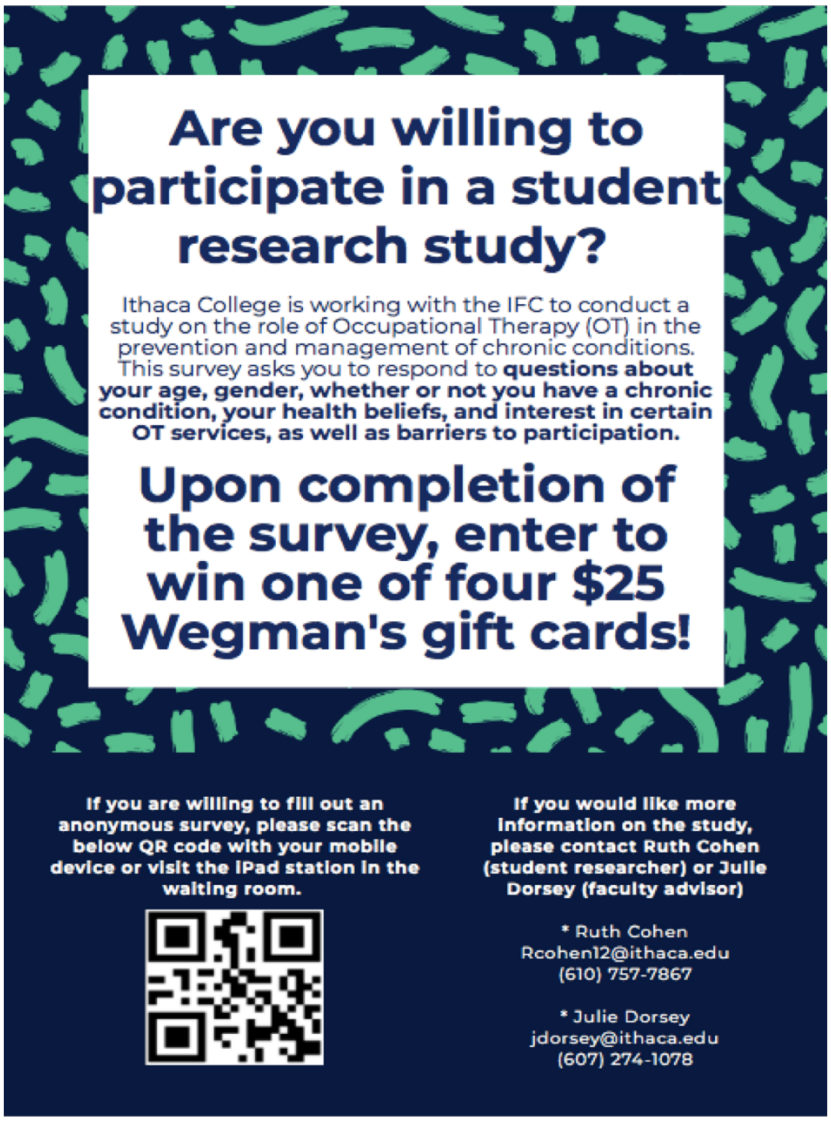
The approval of your study is valid through 11/25/2020, by which time you must submit an annual report either closing the protocol or requesting permission to continue the protocol for another year. Please submit your report by **10/28/2020** so that the IRB has time to review and approve your report if you wish to continue it for another year. The project can be extended up to three years.

Please note that if there are any adverse events resulting from this research, they must be submitted through Axiom.

Sincerely,

Warren Calderone
Director of Corporate, Foundation Relations, and Sponsored Research
Institutional Review Board for Human Subjects Research

Appendix B: Client Recruitment Poster



Appendix C: Client Recruitment Script

For Primary Investigator: Hi! My name is Ruthie Cohen and I am an occupational therapy (or OT for short) graduate student at Ithaca College. For my research project, I am working with the Ithaca Free Clinic to conduct a study about the role of OT in the prevention and management of chronic conditions.

OR:

For Research Assistant: Hi! My name is _____ and I am an occupational therapy (or OT for short) student at Ithaca College. I am assisting with a research project, where Ithaca College is working with the Ithaca Free Clinic to conduct a study about the role of OT in the prevention and management of chronic conditions.

THEN (for both primary investigator and research assistant):

The study is a brief online anonymous survey that asks you to respond to questions about your age, gender, whether or not you have a chronic condition, your health beliefs, and interest in certain OT services, as well as barriers to participation. The time to complete this survey is approximately 5-10 minutes. If you choose to complete the survey, you can be entered into a drawing to win one of 4- $25 gift cards to Wegmans. You do not need to have a chronic condition to participate in the study, and you may skip questions or stop the survey at any time.

Would you like to complete the survey?

If No: Thank you for your time.

If Yes: Thank you! You can either scan the QR code on your mobile device or use one of these iPads to complete the survey.

Appendix D: Provider Recruitment E-mail

Dear Providers at the Ithaca Free Clinic,

Ithaca College is working with the Ithaca Free Clinic to conduct a study on **the role of occupational therapy in the prevention and management of chronic conditions** at the Ithaca Free Clinic. The current study involves completion of a survey that asks you to identify which type of provider you are, your experience working at the IFC, the purposes of your previous referrals to OT services, and your views on OT services for your clients.

Please click here to access the anonymous online survey questionnaire. It will take approximately 5-10 minutes to complete.

If you have any questions, concerns, or would like more information regarding this study, please contact the faculty advisor listed below. For general questions, please contact Abby Gilbert, the Director of the Chronic Care Program at the Ithaca Free Clinic (607-330-1253).

Best Regards,

Ruth Cohen, Primary Investigator
Department of Occupational Therapy
Ithaca College, Ithaca, NY 14850
Rcohen12@ithaca.edu

Julie Dorsey, OTD, OTR/L, CEAS
Faculty Advisor
Department of Occupational Therapy
Ithaca College, Ithaca, NY 14850
(607) 274-1078
jdorsey@ithaca.edu

Appendix E: Client Survey

ITHACA COLLEGE

My name is Ruth Cohen and I am a graduate occupational therapy (OT) student at Ithaca College. As part of my research project, I am studying the role of OT in the prevention and management of chronic conditions. You do not have to have a chronic condition to complete this survey.

I am asking you to complete this electronic anonymous survey ONLY IF YOU ARE AT LEAST 18 YEARS OLD. This survey asks you to respond to questions about your age, gender, whether or not you have a chronic condition, your health beliefs, and interest in certain OT services, as well as barriers to participation. The total time to complete this survey will be about 5-10 minutes. You can skip any questions that you do not want to answer and may withdraw from this study at any time. At the end of the study, you will be prompted to enter a drawing for one of four $25 gift cards to Wegman's.

If you have any questions or concerns about this survey, please contact the faculty advisor listed below. In addition, if you have any questions regarding chronic conditions, please contact the director of the Chronic Care program, Abby Gilbert (607-330-1253), or your primary care physician.

Thank you for your help!

Ruth Cohen

I give my consent to participate in this survey.

- ○ Yes
- ○ No

Please state your age.

Please state your gender.

I am currently in the role of caregiver for another person(s). (example: family member, friend, child)

- ○ Yes
- ○ No

I currently have a caregiver to help manage daily or weekly needs.

- ○ Yes
- ○ No

Chronic conditions are defined broadly as conditions that last one year or more, and require ongoing medical attention and/or limit activities of daily living.

Do you currently have a chronic condition? (Examples: diabetes, cardiovascular disease, anxiety, cancer, obesity, depression, high blood pressure)

- ○ Yes
- ○ No

Does this condition(s) impact your ability to do the everyday things you want or need to do?

- ○ Yes
- ○ No

If yes, please explain how this condition(s) impacts your daily life.

Please indicate your agreement to the following statements (does not matter if you have a chronic condition or not)

	Strongly Agree	Agree	Disagree	Strongly Disagree
I believe that chronic conditions can have a negative impact on daily life.	○	○	○	○
I can identify risk factors for chronic conditions.	○	○	○	○
I can make changes to prevent, or prevent worsening of, chronic conditions.	○	○	○	○
There are barriers (personal or other) to making changes to prevent, or prevent worsening of, chronic conditions.	○	○	○	○
I believe I am at risk for developing a chronic condition or worsening of a chronic condition.	○	○	○	○

What comes to mind when you hear the word "health"?

Occupational Therapy (OT) helps people participate in the things they want to and need to do, such as taking care of one's self, taking care of others, work, leisure, and more. OT helps people engage in daily life through addressing roles, habits, and routines needed at home, in the community or workplace, and in other settings. OT services can also help to prevent illnesses and injuries including chronic conditions.

Please rate your agreement with the following statements.

I would benefit from OT at the Ithaca Free Clinic to address:

	Strongly Agree	Agree	Disagree	Strongly Disagree
Using community resources to manage physical and mental health needs.	○	○	○	○
Understanding of the healthcare system, scheduling appointments, and advocating for my health needs.	○	○	○	○
Managing daily medications.	○	○	○	○

Incorporating exercise routines into my daily life.	○	○	○	○
Techniques for getting to sleep and staying asleep.	○	○	○	○
Exploring new leisure interests and balancing leisure activities with other responsibilities.	○	○	○	○
Managing a work day, finding and maintaining work or volunteer opportunities.	○	○	○	○
Participating in social groups (such as neighborhood, spiritual/religious group)	○	○	○	○
Taking care of others (pets, children, other family members, etc.)	○	○	○	○
Taking care of my home (cleaning, gardening, etc.)	○	○	○	○

Taking care of my home (cleaning, gardening, etc.)	○	○	○	○
Taking care of myself (grooming, dressing, etc.)	○	○	○	○
Participating in formal and/or informal educational classes, programs, and activities.	○	○	○	○
Navigating transportation (driving, public transportation, biking, etc.)	○	○	○	○
Incorporating healthy food into daily life (shopping, budgeting, meal prep, routines etc.)	○	○	○	○

What might prevent you from participating in OT services? (some examples might include transportation, child care, time).

What would support your participation in the above programs of interest?

Is there anything else you would like to tell us?

Appendix F: Client Survey to Win Gift Card

You have reached the survey to enter to win one of four $25 gift cards to Wegman's. Your identity will in no way be linked to the information you provided in the previous survey and your responses to the previous questions will remain anonymous.

If you would like to be entered in this drawing, please enter the information below.

Please state your first and last name.

Please enter a good phone number to reach you.

Please enter your e-mail address.

I prefer to be contacted by:

- ○ Phone call
- ○ Text
- ○ Email

Appendix G: Provider Survey

ITHACA COLLEGE

My name is Ruth Cohen and I am a graduate occupational therapy (OT) student at Ithaca College. As part of my master's research project, I am studying the role of OT in the prevention and management of chronic conditions.

I am asking you to complete this electric anonymous survey ONLY IF YOU ARE AT LEAST 18 YEARS OLD. This survey asks you to identify which type of provider you are, your experience working at the IFC, the purposes of your previous referrals to OT services, and your views on OT services for your clients. The total time to complete this survey will be about 5-10 minutes. You can skip any questions that you do not want to answer and may withdraw from this study at any time.

If you have any questions or concerns about this survey, please contact the faculty advisor listed below. In addition, if you have any questions regarding chronic conditions, please contact the director of the Chronic Care program, Abby Gilbert (607-330-1253), or your primary care physician.

Thank you for your help!

Ruth Cohen

I give my consent to participate in this survey.

- ○ Yes
- ○ No

Please check your area of involvement at the Ithaca Free Clinic.

- ○ Nurse/nurse practitioner
- ○ Chiropractor
- ○ Physician
- ○ Acupuncture
- ○ Massage therapist
- ○ Women's health
- ○ Other

Please describe your involvement at the Ithaca Free Clinic.

How many years have you worked at the Ithaca Free Clinic?

Have you ever referred a client to occupational therapy at the Ithaca Free Clinic?

- ○ Yes
- ○ No

What was the purpose of the referral(s)? Please check all that apply.

- ☐ Activities of Daily Living (ADL) skills
- ☐ Higher Level ADL skills
- ☐ Strength
- ☐ Sensation
- ☐ Range of Motion
- ☐ Neurological issues
- ☐ Return to Work
- ☐ Pain management
- ☐ Coordination
- ☐ Cognition
- ☐ Mental Health issues
- ☐ Other

If other, please describe the purpose of the referral.

Occupational Therapy (OT) helps people participate in the things they want to and need to do, such as taking care of one's self, taking care of others, work, leisure, and more. OT helps people engage in daily life through addressing roles, habits, and routines needed at home, in the community or workplace, and other settings. OT services can also help to prevent illnesses and injuries including chronic conditions.

Please rate your agreement to the following statements.

I would refer clients to OT at the Ithaca Free Clinic to address:

	Strongly Agree	Agree	Disagree	Strongly Disagree
Using community resources to manage physical and mental health needs.	○	○	○	○
Understanding of the healthcare system, scheduling appointments, and advocating for health needs.	○	○	○	○
Managing daily medications.	○	○	○	○
Incorporating exercise routines into daily life.	○	○	○	○
Techniques for getting to sleep and staying asleep.	○	○	○	○
Exploring new leisure interests and balancing leisure activities with other responsibilities.	○	○	○	○
Managing a work day, finding and maintaining work or volunteer opportunities.	○	○	○	○

Participating in social groups (such as neighborhood, spiritual/religious group).	○	○	○	○
Taking care of others (pets, children, other family members, etc.).	○	○	○	○
Taking care of the home (cleaning, gardening, etc.).	○	○	○	○
Taking care of self (grooming, dressing, etc.).	○	○	○	○
Participating in formal and/or informal educational classes, programs, and activities.	○	○	○	○
Navigating transportation (driving, public transportation, biking, etc.).	○	○	○	○
Incorporating healthy food into daily life (shopping, budgeting, meal prep, routines, etc.)	○	○	○	○

Please discuss how the above mentioned OT services might be helpful to your clients. If you do not think they are helpful, please discuss why.

Do you experience any barriers to making referrals to OT services? If yes, please describe.

What do you perceive as the barriers for clients to follow through with their appointments in general? If you are able to comment, what are the barriers for following through with OT appointments?

What comes to mind when you hear the word "health"?

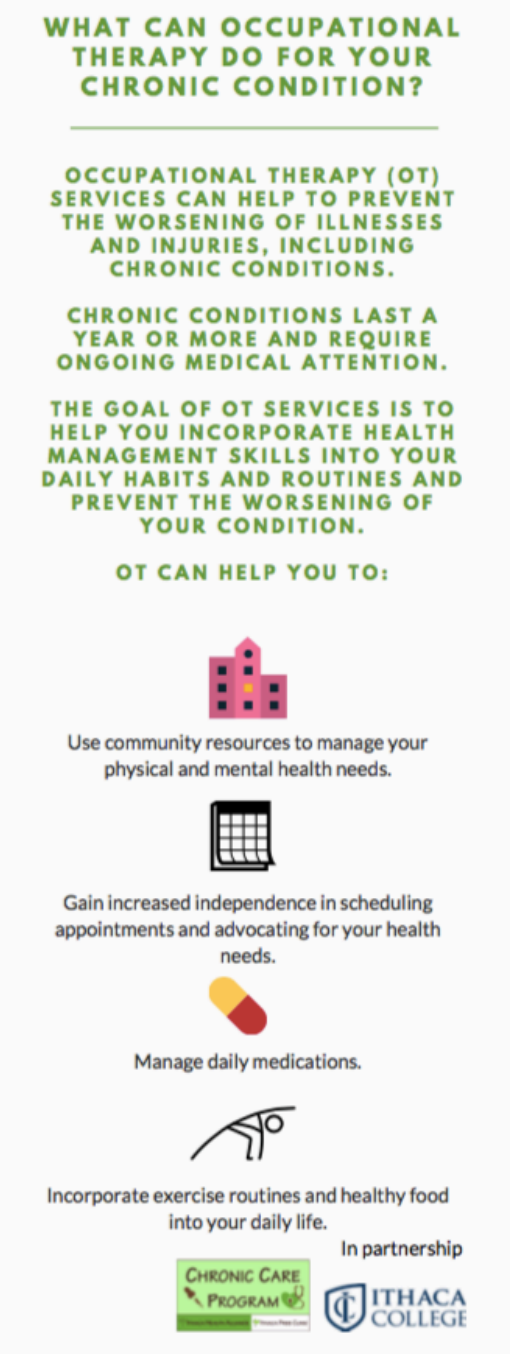
What do you think positively impacts the health of your clients?

What do you think negatively impacts the health of your clients?

Is there anything else you would like to tell us?

Appendix H: Insert for Chronic Care Program at the Ithaca Free Clinic

(Front)



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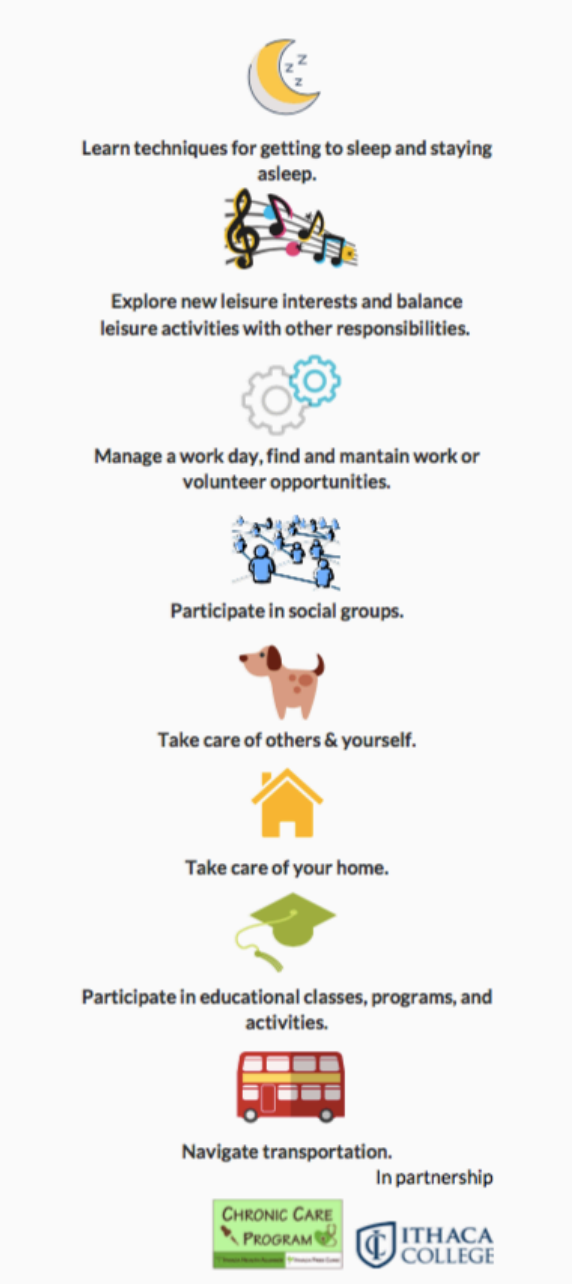
Learn techniques for getting to sleep and staying asleep.
Explore new leisure interests and balance leisure activities with other responsibilities.
Manage a work day, find and mantain work or volunteer opportunities.
Participate in social groups.
Take care of others & yourself.
Take care of your home.
Participate in educational classes, programs, and activities.
Navigate transportation.
In partnership
CHRONIC CARE PROGRAM
ITHACA COLLEGE